

**“IT GAVE ME RELIEF... IT GAVE ME CONFIDENCE”- THE ONLINE
HEALTH INFORMATION SEEKING EXPERIENCES OF ADULTS WITH
CHRONIC HEALTH CONDITIONS**

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Abstract

Background- The recent modernisation of the United Kingdom (UK) National Health Service (NHS) has included a number of sizeable reforms that have emphasised partnership relationships between patients and professionals, and the importance of individuals taking a more active role in their care. Many of these changes have been specifically geared towards patients with chronic health conditions, who are recognised as imposing the largest strain on health services worldwide. This modernisation has occurred in parallel with a huge increase in the number of people within the UK who are turning to the internet for health information in order to become more informed about their health and treatment regimes. Despite this increase in the prevalence of online health information (OHI) seeking, relatively little is known about how people seek OHI and the impact it has on their lives and relationships with others.

Overall Study Aim- This study sought to understand the OHI seeking experience of individuals with chronic health conditions by using an innovative mixed-methods approach to collect a breadth and depth of relevant information on the topic.

Design – One hundred participants were recruited from local support groups for various chronic health conditions. The participants in the first stage of the study completed one of two questionnaires, depending on whether or not they had sought OHI in the past. The design and focus of stage two of the study was guided by the findings from stage one, and subsequently focused on the experiences of older adults with chronic health conditions seeking OHI. A descriptive phenomenological approach was adopted in order to provide rich descriptions of patients' experiences. Six participants were purposefully selected from a parallel sample to the stage one respondents.

Findings- The results from stage one provided a breadth of information about the OHI seeking experience for people with chronic health conditions. Findings suggested that health professionals were still the most important source of health information for users and non-users of OHI; that patients had an awareness of the inconsistencies in terms of OHI quality; and identified the perceived ease with which useful and relevant OHI was located. A further key finding was that high age, low education levels and low internet usage not only acted as barriers to OHI seeking for participants, but also had a negative impact on participants' perceptions of the positive outcomes of OHI seeking, such as confidence in decision-making or engaging in discussions with

health professionals. Moreover, some non-users demonstrated that they felt they were “too old” to engage in OHI seeking. Stage two findings demonstrated 5 key themes: patients taking responsibility for their health; their expectations of OHI; explicit confidence in their own ability to discern OHI and concern for others to do the same; the selective nature of OHI sharing between patients, and patients and health professionals; and the reinforcement of social sharing networks where positive and useful OHI is shared freely.

Conclusion- Although older adults within this sample were less likely to engage in, and perceive the positive outcomes of OHI seeking than their younger counterparts, some older adults were successfully engaging in the OHI seeking experience, and perceiving the constructive effects of this experience such as empowerment. Furthermore both stages of the research demonstrated the valuable role health professionals play in supporting patients seeking OHI.

Implication- This study demonstrates a need for health professionals to actively support patients in seeking OHI. In doing so, this could reinforce OHI seeking behaviour, and assist patients in effectively searching for and appraising OHI.

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Chapter 1. Introduction

In recent years, the internet has become a vitally important source of health information for the general public. Recent estimates suggest that, within the United Kingdom (UK), around 42% (n=965) internet users have recently sought health information online, a figure that is rapidly growing year on year (Office of National Statistics, 2009). The increased popularity of individuals seeking health information online reflects the concurrent modernisation strategy of the National Health Service (NHS) outlined by the UK Department of Health (DoH). The DoH is making a number of sizeable reforms to ensure that the development of the health service reflects societal changes such as the popularisation of consumerism and social citizenship, as well as the emergence of the digital information age. These reforms include progression from the traditional paternalistic model of health care that has become endemic within the NHS (Coulter, 1999) to one that locates patients at the centre of the health service (Department of Health, 2009) and acknowledges their role in ensuring positive health outcomes. This reformation has huge potential to improve upon traditional ‘cooperation guidance’ care strategies that have been adopted by the NHS in the past whilst dealing with individuals living with chronic health conditions. These patients are the largest strain on health services worldwide, with health professionals struggling to provide the information required to promote high-quality care through the traditional model of health care. By encouraging patients to independently seek health information online and therefore engage in self-care of chronic health conditions, there is the potential to narrow the gap between the demand for high quality health care and the availability of services by empowering patients to take responsibility for their care.

The popularity of the idea that patients should be able to take a more active role in their health care by becoming increasingly informed has led to the development of a whole new academic discipline dedicated to studying the phenomenon. Consumer health informatics is the branch of medical informatics that analyses consumers’ needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers’ preferences into medical information systems (Eysenbach, 2000). Despite numerous studies being conducted within this new field, there are still many questions that remain unanswered, inhibiting our overall knowledge of online health-seeking behaviour.

The overarching aim of this research was to develop understanding of the online health information (OHI) seeking experiences of adults with chronic health conditions, and therefore make a contribution to knowledge in the field of consumer health informatics. This overarching aim was broken down into a more specific set of aims and objectives:

Aim: Breadth- To collect broad data relating to the overarching research aim. In order to effectively communicate the aim it was broken down into 5 more specific objectives:

Objectives: Breadth-

- To investigate how people make choices about locating OHI.
- To examine how they decide if it's reliable.
- To explore what they do with OHI after they find it.
- To examine how OHI influences decision-making.
- To investigate how individuals perceive the response from others to their online information- seeking behaviour.

Aim: Depth- To collect a depth of data relating to the overarching research aim. Stage one findings allowed for a more specific objective to be outlined in order to demonstrate how this aim would be realised.

Objective: Depth- To explore in a detailed way how searching for OHI had become a meaningful activity for older adults with chronic health conditions. * This was then broken down into six specific related research questions for stage two:

Research questions: Depth- How older adults with chronic health conditions experience:

- Looking for health information online*
- Being unable to find health information online *
- Finding poor quality health information online *
- Online health information helping them understand something better *
- Online health information making them feel confident*

- Sharing online health information with a health professional *
- Sharing online health information with friends, family or support group peers *

Aim: Research methods-A further aim of the research was to review and develop mixed method research techniques.

* (Emerged from stage one findings)

In order to develop a research project that could provide both breadth and depth of information relating to the experiential aims, a pragmatic approach to research design was utilised, which ensured that the study design was guided by the aims of the research as opposed to any researcher preferences or bias. This led to the development of a sequential mixed-methods research design that drew on the strengths and minimised the weaknesses of both traditional qualitative and quantitative research techniques.

Stage one utilised two predominantly quantitative questionnaires to gather broad data relating to the experiences of OHI seeking for adults with chronic health conditions, and the barriers to OHI as perceived by non-users. The findings from this stage were utilised to inform the focus of the second qualitative stage of the study. Stage two used in-depth phenomenological interviews to explore, in a detailed way, how searching for health-related information online became a meaningful activity for those adults living with chronic health conditions.

As well as making a significant contribution to knowledge in the field of consumer health informatics in terms of breadth and depth, an additional objective of the research was to review and develop innovative mixed-methods research techniques in order to make an original contribution to this area of research methods. The final aim of the research was to produce data that could be practically utilised to inform the

training of health professionals, and therefore help develop their understanding of the nature of the phenomenon of OHI seeking.

Chapter 2. Background

Chronic Health Conditions

Frequent attempts have been made in the past to provide a definition of ‘chronic health conditions’. This task is made more complicated because the phrase is also often used interchangeably within research and general publications with other terms such as long-term conditions, chronic illness or chronic disease. The use of multiple terms that are sometimes defined uniquely and sometimes used interchangeably provides specific challenges when comparing research and deciding on an appropriate phrase for use in future studies. The current study will adopt the term ‘chronic health conditions’ because it is felt that terms which include the words ‘illness’ or ‘disease’ predefine individuals within the sick role and subsequently have overly negative connotations. Although the commonly cited term ‘long term conditions’ also provides an appropriate form of expression, the term ‘chronic health conditions’ was more widely present within the literature cited within the current study (Perrin et al., 1993, Stein et al., 1993, Barlow et al., 2002, O’Halloran et al, 2004) and therefore was considered more appropriate.

Although definitions for chronic health conditions vary, duration is the most common, and often solitary, criterion used to define this term (O’Halloran et al., 2004). While common definitions are in agreement that chronic health conditions are conditions that are of a prolonged duration, the actual length of time for classification varies commonly between 3 and 12 months, which is a significant area of contention (Perrin et al., 1993, Stein et al., 1993, O’Halloran et al., 2004). As opposed to using the commonly cited criterion of duration, the Department of Health (DoH) describes the term ‘chronic disease’ as diseases that medical interventions can only control not cure, and states that the life of a person with a chronic condition is forever altered, with no return to the so-called ‘norm’ (Department of Health, 2004b). Table 1 demonstrates a comparison of the assumptions and characteristics of acute and chronic health conditions.

Acute Health Conditions	Chronic Health Conditions
Often quick onset	Often gradual onset
Limited duration	Duration length for classification generally ranges between 3–12 months within the literature. The DoH provides no specific duration for classification other than ‘lengthy’.
Usually single cause	Usually multiple changing causes
Diagnosis is more simple and reliable	Diagnosis is complicated and uncertain
Possibility of cure	No possibility of cure – only controlled using medical interventions
Minimal uncertainty	Uncertainty pervasive
Health professionals normally have far more information than patients	Health professionals and patients have complementary knowledge

Table1. A comparison of the assumptions and characteristics of acute and chronic health conditions. Adapted from information taken from (Holman and Lorig, 2000, Department of Health, 2004b, O'Halloran et al., 2004)

The prevalence of chronic health conditions is increasing globally, with 60% (n=6180) of adults in England now reporting to live with a chronic health condition, and with many of those individuals reporting to live with multiple conditions (BHPS, 1991, Department of Health, 2004b). In addition, estimates suggest that the United Kingdom (UK)'s 65 years and older population will increase from 35 million in 2000, to 53 million in 2020 (Bodenheimer et al., 2002), swelling the size of the age group with most increased prevalence of chronic health conditions. This predicted expansion in incidence of chronic health conditions could present huge challenges for patients and the health services that they utilise worldwide. Patients with chronic conditions are the largest strain on health systems globally, with 80% (n=8240) of UK general practitioner (GP) consultations being taken up by patients with chronic health needs (BHPS, 1991). Despite this fact, healthcare professionals may only interact with patients living with chronic health conditions for a few hours every year, leaving the patients for the rest of the time to manage their own conditions (Department of

Health, 2004b). The need to effectively support patients in managing their own chronic health conditions is increasingly viewed as an essential part of developing the future of healthcare services worldwide. This form of condition management or 'self-care' can be defined as the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002). Self-care involves the at-home management tasks and strategies that an individual adopts in order to reduce the impact that their condition makes on their physical health status and overall wellbeing (Clark et al., 1991, Wilson, 2001). In short, self-care refers to the thousands of hours each year that patients with chronic health conditions spend away from healthcare professionals managing their own chronic conditions. This form of condition management has the potential to bridge the gap between patients' needs and the colossal demands on our health services (Barlow et al., 2002). Such possibilities have been noted by the DoH, which has presented the theme of self-care as an important component of recent health policy.

Government Health Policy

Patient-centred approach

Since 1998, UK government health policy has referred to the importance of patients taking an active role in their own health care (Department of Health, 1998, Department of Health, 2000, Department of Health, 2002, Department of Health, 2005, Department of Health, 2009). The *Information for Health* strategy (1998) described the aims of the policy as to ensure patients, carers and the public have the information necessary to make decisions about their own treatment and care, and influence the shape of health services generally. Similar themes were echoed within the *NHS Plan* (2000), which discussed redesigning the National Health Service (NHS) around the needs of the patients, and providing them with increased power to influence health services. A further sense of urgency was created by the *Bristol Royal Infirmary report* (Department of Health, 2002), where the notion of patient-centred health care was identified as a possible solution for reform, alongside increases in the amount of health information made available to patients and the development of partnership relationships between patients and professionals. Later, in 2005, the NHS published *Creating a patient-led NHS: Delivering the NHS Improvement Plan*, which built on the themes of patient participation outlined within previous policy and

explained the importance of self-care in terms of patients living with chronic health conditions (Department of Health, 2005). More recently, a number of further policies have been outlined and developed relating to enabling patient healthcare participation in specifically managing chronic health conditions (Department of Health, 2004b, Department of Health, 2006, Department of Health, 2007a, Department of Health, 2008). Such policies demonstrate the potential for self-care to revolutionise the way chronic health conditions are managed within the UK health service. The suggestion made by the DoH is that, by providing patients with the information they require to take an active role in their chronic health care, this will lead to the emergence of expert patients who are empowered to self-manage their own conditions.

Expert Patients

The frequently adopted DoH term ‘expert patient’ was first identified within the white paper *Our Healthier Nation – Saving Lives* (Department of Health, 1999). This document introduced the Healthy Citizens programme designed to help individuals and their families make decisions about their healthcare and treatment regimes. This suggested programme of change included the development of telephone and internet services for patients, the introduction of health skills programmes and the creation of the Expert Patient Programme (EPP) with the vision to help individuals manage their own chronic health conditions. The white paper suggests that, so far, too little has been done to help people with chronic disease to play a part in managing their own condition and announces the intention to develop a task force to design the new Expert Patients Programme to address the needs of the very many people in this country with a chronic disease or disability (Department of Health, 1999). The theory behind *Saving Lives* is that individuals living with chronic health conditions are often the ‘experts’ at managing and living with their conditions day-to-day, and therefore hold complementary information to that which can be provided traditionally by health professionals. This theory is derived from philosophical thought that ‘the lived is greater than the known’ (Merleau-Ponty, 1962); put simply, the individual living the experience is in some respects more of a true expert than the person who has merely studied it. The realisation is that patients with chronic health conditions are more likely to have a different form of knowledge based on their unique experiences, which has the potential to complement the academic knowledge of health professionals.

The specific model on which the tenets of the EPP were based was developed at Stanford University in the mid-1990s (Lorig et al., 1996). Within this research, Lorig and colleagues identified the 12 ways in which people can help themselves deal with long-standing illnesses, which are listed in full within the 1999 DoH white paper (Department of Health, 1999). These 12 ways in which self-care can help people living with chronic health conditions are based on the same template as the US Chronic Disease Self-management Programme that had been operating prior to Lorig et al.'s 1996 paper.

The EPP that was developed is based on a template of six weekly sessions each lasting 2.5 hours, including topics such as dealing with pain and fatigue, coping strategies, relaxation, exercise, nutrition and communicating with family, peers and healthcare professionals (Expert Patients Programme Community Interest Company, 2009). The courses are led by a mixture of course-trained 'lay' individuals and health specialists, and are aimed at empowering individuals to take a more active role in the management of chronic health conditions by equipping them with additional information and confidence.

A small number of short-term evaluations of the EPP have been conducted to assess its feasibility, application and ability to satisfy the objectives outlined by the DoH (Department of Health, 1999). The 2006 national evaluation of the EPP was unable to prove the absolute effectiveness of the programme despite reporting high levels of participant satisfaction in the course (Kennedy and Gately, 2005, Rogers et al., 2005). This evaluation demonstrated that the course had a moderate effect on the self-efficacy of participants and a smaller, less notable impact on increasing participants' energy levels. There was, however, no change in health services utilisation – one of the main objectives of the programme (Kennedy et al., 2005). Similar research findings were also reported in a further independent study (Wilson et al., 2007). This research revisited the critique of the EPP by utilising a mixture of focus groups, in-depth interviewing and participant observation of the EPP in practice. In concordance with the aforementioned evaluation, this paper highlighted that some participants noted evolving self-efficacy, feelings of control and increased motivation for activity. This research also uncovered the potentially 'paradoxical nature' of the EPP (Wilson et al., 2007), in that it has the potential to reinforce the traditional medical paradigm

whilst simultaneously supporting the subjective experience of living with a chronic health condition.

The adaptation and development of the EPP as a technique used to encourage patient participation in condition management demonstrates the intention shown within the National Service Frameworks to mark a new reformed phase in the management of chronic health conditions. The intention shown is that an evidence-based template will be provided to establish improved quality standards for the delivery and maintenance of health services that firmly locates the patient at the heart of the healthcare system (Department of Health, 2000). However, making such dramatic changes to the traditional model of health care, and identifying patients as information enabled experts, has serious implications for the relationship between patient and practitioner.

‘The relationship between service and patient is too hierarchical and paternalistic. It reflects the values of 1940s’ public services. Patients do not have their own health records or see correspondence about their own healthcare. The complaints system in the NHS is discredited. Patients have few rights of redress when things go wrong’. (Department of Health, 2000, p.30).

The aforementioned concept of recognising and educating patients as experience-led experts in their own chronic health conditions relies on the cooperation of health professionals to acknowledge patients in this new position of increased power. Previous research into the attitudes of health professionals towards their patients’ knowledge of their own chronic health conditions has demonstrated a lack of acceptance on the part of health professionals regarding their patients’ abilities to make decisions relating to their own care (Thorne et al., 2000) and an unwillingness to accept the idea of being challenged by knowledgeable patients (Wilson et al., 2006). This unwillingness to accept the information power of the patient is rooted within the traditional paternalistic hegemony that exists between patient and healthcare professional. This power relationship is based on the idea of a unidirectional flow of health information and advice from the knowledgeable professional to the lay patient, creating and maintaining an unhealthy dependency on

these professionals for health services. This paternalistic model has been described as ‘endemic’ within the NHS, and has been criticised as having ‘no place’ within a modern model of health care (Coulter, 1999). The need for a shift in the power imbalance has also been recognised by UK policy makers who have promised reform in the way of partnership (Department of Health, 1996, Department of Health, 2000). The patient-centred revolution of the UK healthcare system as outlined by the DoH promotes the concept of an egalitarian relationship between patient and professional as opposed to the traditional ‘cooperation guidance’ model, and a move to a model based around ‘mutual participation’ where power and responsibility for health and treatment are shared between both parties (Mead and Bower, 2000).

Moving Forward- The Coalition

As this thesis is submitted, the newly formed and instated UK coalition government is demonstrating a strong commitment to the themes of patient choice, partnership and to the development of online services as outlined by the previous labour government. Specifically the white paper *Equity and excellence: Liberating the NHS* (DOH, 2010a) has resulted in a consultation running between October 2010 and January 2011 that will outline the themes of ‘greater choice and control’ for patients (DOH, 2010b), and demonstrates the government’s intentions for an ‘information revolution’ (DOH, 2010c). The consultation document *Liberating the NHS: Greater Choice and control* (DOH, 2010b) outlines the coalition government’s intention to build on themes of patient choice present within previous health policy, and help develop the partnership approach in order to ensure shared decision making becomes standard practice. A further consultation document *Liberating the NHS: An Information Revolution* (DOH, 2010c) describes the coalition’s agenda regarding their commitment to integrating online services within the NHS in order to promote patients accessing information, and communicating with health professionals online. These consultation documents demonstrate that patient choice, partnership and the promotion of online health activity will be ongoing themes throughout this government’s health policy.

Societal Changes

The aforementioned demonstrates that over recent years the NHS has engaged in an ongoing process of modernisation of its overall approach and services. The previous

literature demonstrates that one of the key motivations for this reform was to reduce the strain on health services in terms of patients with chronic health conditions. However, the NHS has also developed a number of strategies designed to meet the changing needs of its patients in order to ensure effective modernisation. Specifically, numerous societal changes have affected the expectations of patients in terms of what they want from their health service providers and the role that they wish to play in managing their own conditions. These societal changes that have acted as a catalyst for modernisation include the development of consumerism (Lupton, 1997, Zadoroznyj, 2001), social citizenship (Milewa et al., 1998, Marinetto, 2003) and the increasing popularity of the internet as a health information source (National Statistics, 2009).

Consumerism

The rise of consumerism as a predominant social and economic philosophy within western societies has had a major effect on the expectations of the general public. In terms of their health, this consumerist culture has led to patients having renewed expectations of health services in terms of the choice and efficiency of services that reflect consumerist marketplace values. In an attempt to remain relevant and meet the needs of patients, these tenets of consumerism can be witnessed throughout UK health policy (Mills, 2005). The weight of their effect can be recognised particularly within policy relating to the ongoing theme of ‘patient choice’, which reflects one of the key features of consumerist culture: providing the public with options in terms of services. Reforms relating to increased patient choice are based on the consumerist theory that, by providing the individuals with a selection in terms of services, a familiar feature of the market is introduced to the system: competition. The introduction of competition is a renowned method of driving out inefficiency and improving quality, because the consumer is faced with a range of suppliers competing to offer the service to them (Mills, 2005), and therefore has the potential to play an important role in meeting patients needs.

Several recent UK health reforms reflect this consumerist expectation for a choice in services. In 2003, Choose and Book, the NHS e-booking software, was procured as part of the National Programme for Information Technology (NPfIT). This service was designed to enable patients needing an outpatient appointment to choose which

hospital they are referred to by their GP, and to book a convenient date for their appointment. However, more recently, both the NPfIT and the Choose and Book service have been placed at the centre of ongoing controversy due to the cost and scope of the NPfIT programme and the delays and functional problems encountered by Choose and Book. The 2004 *Better information, better choices, better health* publication (Department of Health, 2004a) set a national target for a three-year programme whereby, in 2008, individuals would be fully involved in decisions about their health care. This paper not only discussed access to information and health records, but also addressed the important issue of quality signposting in order to give the public the confidence to judge the quality of health information by assisting their navigation around the huge amount of health information available. In line with the concept of patient choice, in 2007 former health secretary Patricia Hewitt announced two additional measures to give patients more control over their health care (Department of Health, 2007b). The announcement promised that by the end of 2008 patients would be able to choose from any hospital or clinician who meets the NHS standards and costs, and the development of a 'new choice' super site (Department of Health, 2007b). The same sentiments have recently been echoed in *NHS Next Stage Review Final Report* (Darzi, 2008), which states one of its aims as being to introduce a new right to choice in the first NHS constitution. This includes the right to choose both treatment and providers and to information on quality in order to make informed decisions. It also includes piloting personal health budgets to give individuals and families greater control over their own care.

Although the DoH has adopted aspects of the consumerist approach, such as choice and competition between services within the NHS, it is dangerous to presume that the healthcare system wholly adopts a consumerist approach, or that patients operate in the exact same manner as consumers. Although a number of researchers have described patients as healthcare consumers (Jadad and Gagliardi, 1998, Eysenbach, 2000, Eysenbach and Jadad, 2001), there are certain aspects of the patient experience that do not fit the traditional consumerist mould. For instance, patients with chronic health conditions are looking for health information out of necessity as opposed to choice as is normally the case within consumerist culture. In terms of the reflection of consumerism on the health service, adopting aspects of the consumerist approach has the potential to improve patient satisfaction by meeting expectations in terms of

choice and efficiency. Despite this potential, it is difficult to see how this model could be wholly adopted by the current UK health system. The market is an environment where the patient could never be truly confident that their needs are paramount, as service is put second to profitability (Mills, 2005). In addition, this approach has the potential to inhibit patients taking responsibility for their own health, because consumerism is based on commercial relationships and is signified by high expectations in terms of the service that is provided. Adopting this approach entirely could fail to motivate patients to take a more active role in their health care, and instead could lead to increased reliance.

Citizenship

In addition to patients increasingly having expectations in terms of choice and efficiency, the rise of active citizenship has led to patients having specific expectations in terms of agency, rights and ownership over community services and resources. The theory behind citizenship is that ‘we are all in this together’ and that we have responsibilities towards the whole as opposed to just rights as consumers (Turner, 1990). The concept of citizenship respects the agency and power of the individual and groups of individuals; however, unlike consumerism, which could be described as competitive, it promotes concepts of cooperation between services and the public. Within the field of health care, emphasising the citizenship approach would suggest that individuals have ownership over their health and wellbeing, and that systems and services should be designed with this in mind (Todres et al., 2007). Therefore, in an attempt to meet the needs of patients, as well as developing a number of market-based consumerist themes within its plans to modernise the NHS, the DoH has also involved aspects from citizenship to meet the expectations of patients in terms of empowering them to take a more active role in their health and treatment regimes. In addition, the DoH has accepted a role in developing health services generally through patient and public involvement.

The information age

The third societal change influencing patient expectations in terms of their health is the development of the internet as an information resource. The widespread availability of health information via the internet has enabled patient access to information relating to acute and chronic health conditions on demand. In 2009, a UK

government document reported that 18.31 million (70%) households in Great Britain had internet access at home, an increase of 1.85 million (10%) over the previous year, and over 7 million (60%) since 2002 (Office of National Statistics, 2009). The same survey also demonstrated that 42% (n=965) of internet users had accessed the internet to seek health information within the three months prior to the survey being conducted (Office of National Statistics, 2009). As the popularity of the internet as a health information source has developed, the number of health-related websites and online tools has increased dramatically to cope with the demand, leading to massive boosts in the development and distribution of online health information (OHI) (Oermann et al., 2003, Sillence et al., 2007). In order to reflect this societal change, meet the needs of the patients and respect patients' information-enabled status, the development of online services is a priority in the modernisation of the NHS (Department of Health, 1998, Department of Health, 2000, Department of Health, 2001a, Department of Health, 2001b).

In 1998, the Information for Health strategy announced that it aimed to ensure that patients, carers and the general public have the information required to make decisions about their own treatment and care, and to influence the shape of the NHS. In order to achieve 'patient-led care', the Information for Health strategy announced plans to develop NHS Direct online in order to disseminate health information to patients. It also promised to develop widely available electronic health records and electronic patient records; to provide the general public with accredited, independent background information on conditions as well as provide general lifestyle and health information; and that arrangements would be put in place to assist the general public in assessing consistent, comprehensive, comprehensible and up-to-date advice from accredited sources on a wide range of health issues.

Following the Information for Health strategy, the need to develop online services was reiterated within the NHS Plan (2000) which was heralded as the most radical reorganisation of the NHS since it was founded in 1948 (Department of Health, 2000). Although the NHS Plan only provided limited information on the role of the internet in the modernisation of the NHS, a supporting document called *Building the information core implementing the NHS Plan* discussed the important role the internet would play in ensuring that patients could be empowered to take a more central role

in their health care (Department of Health, 2001a). Once again, this document discussed the DoH's intentions to develop NHS Direct and improve patient access to their own medical records.

In June 2001, the DoH published a new strategy for developing IT within the NHS called *Delivering a 21st Century Support for the NHS – A National Strategic Programme*, promising that citizens would be able to obtain information over the phone or via the internet 24 hours a day, and that patients can expect up-to-date information regarding their symptoms online via the internet or digital television (Department of Health, 2001b). This strategy laid the foundations for the NPfIT, which was established formally in October 2002 in an attempt to coordinate previous reports on IT strategies for the NHS. One of the major aims of this programme was to develop the patient records described in *Information for Health* and provide patients with online access to these in order to aid informed decision making and information seeking. This initiative was named Healthspace and aims to provide patients with a range of online services, including a space to track one's own health and lifestyle information, a summary care record and access to the aforementioned patient choice services such as Choose and Book.

Conclusion

Since the former government came into power in 1997, the DoH has undergone a number of policy reforms designed to modernise the NHS in line with recent social changes, such as the rise of consumerism (Lupton, 1997, Zadoroznyj, 2001), social citizenship (Milewa et al., 1998, Marinetto, 2003) and the increased popularity of the internet (Office of National Statistics, 2009). As cited within *The NHS Plan* (2000), the DoH stated that the NHS is a 1940s system operating within a 21st century world, and should be redesigned with the patient at the centre. Various policies have been implemented since in order to redesign the paternalistic model of health care into one based around partnership and mutual participation. These changes have the potential to take some of the strain currently exerted on the NHS by patients with chronic health conditions, through empowering patients to take an active role in self-management. One of the ways in which the NHS has encouraged patients to self-manage their chronic conditions is by providing them with online services and information that will allow them to make more informed decisions relating to their

Background

health and wellbeing. Despite an increase in the number of people using the internet for this purpose within the UK (Office of National Statistics, 2009) there is still a lack of research into how individuals want to work with health professionals and the implications for those who do not wish, or are unable to gain access, to high-quality health information online. In addition, relatively little is known about the experiences of adults with chronic health conditions seeking health information online, how they utilise this information and the reactions that they encounter to this behaviour.

Chapter 3. Literature Review

Introduction

An ongoing literature search was conducted throughout the study, with the primary objective of identifying the overall scope and direction of research within the field of online health information (OHI) seeking. The designated end date for literature searches to contribute towards the literature review was 01/04/10 to allow for the writing up of the final thesis to commence. After this date, a smaller literature search was conducted to contribute to the discussion section, with a cut-off date of 01/08/10. No lower cut-off date was included in either search because the relatively recent development of the internet provided a natural lower boundary for literature regarding OHI seeking. The initial database searches were conducted prior to finalising the formal research proposal (11/07), and once again more comprehensively before preparing the document for ethical approval (02/08). This initial process produced a trajectory of research relating to individuals' OHI-seeking behaviours. The databases that were included within this search were Academic Search, SpringerLink, Web of Science, Science Direct, PubMed, Medline, CINAHL, PsychINFO, BNI and Cochrane. A variety of search terms were used to ensure that a high volume of background research was located. These included: online health information, internet healthcare, online health care, e-health and consumer health informatics. Publications were selected that had been written in the English language.

This preliminary literature search strategy proved that electronic searching was not as comprehensive as initially anticipated; nor was it a simple process. Therefore, more creative searching strategies were utilised to ensure that potentially relevant publications were acknowledged. Primarily, reference lists were carefully scrutinised to help discover additional publications that were not identified through the initial database search. In addition, key authors in the fields of study were recognised, and individual searches were conducted to locate their published works. Also, large-scale research was sought from independent organisations such as Pew Internet and Harris Interactive, as well as reports from United Kingdom (UK) Office of National Statistics. Finally, a number of relevant conferences were attended, and reference lists from pertinent presenters were requested in order to aid the ongoing literature search. Regular electronic searches were conducted continually throughout the research

process until the cut-off date, to ensure that relatively recent publications were included within the literature review.

Presentation of Literature

The initial review of the literature is divided into four main parts. The first of these four sections provides a discussion of how people look for health information online. The second of the four sections contributes a summary of the literature concerning the potential of OHI. This branch primarily involves an examination of the work around the potential of OHI to have a positive effect on the lives of patients by improving factors such as confidence; self-efficacy, empowerment and control; decision-making; and discussion with health professionals. The third of the four sections looks at the barriers to OHI. This area includes an examination of the literature on the internet quality debate, the differences between OHI seekers and non-seekers, and the barriers facing individuals to accessing OHI. The fourth and final part of the literature review discusses the role of others in OHI seeking. This section examines background literature relating to sharing OHI, the reactions perceived by the individuals involved, and the potential effects of OHI-seeking on relationships with others.

How People Look for Health Information Online

The internet was invented in the late 1980s with the intention for it to be a 'universe of network accessible information' in order to help individuals locate a wealth of information from 'anywhere' (Berners-Lee, 1997). In line with this initial philosophy, in 1993 it was announced that the web would be able to be used for free by anyone to develop and improve. However, by 1998, still only 9% (n=629) of UK households had access to this universe of information (Office of National Statistics, 2003). More recently, developments such as affordable high-speed home internet connections and the popularisation of mobile internet have contributed to this figure growing rapidly. In 2009, it was reported that 70% (n=2297) of UK households had access to the wealth of worldwide information and services online (Office of National Statistics, 2009). Furthermore, it was estimated that around 90% (n=2067) of these UK households access the internet with a broadband connection as opposed to traditional dial-up (Office of National Statistics, 2009). The increase in popularity of broadband as opposed to traditional dial-up connections has provided internet users with high-speed connections that facilitate new ways for information to be shared online e.g.

through high-quality video and audio. Such developments have the potential to increase and expand the number of different activities available to internet users worldwide.

Internet activities

Currently, UK internet users report engaging in numerous internet activities online, such as sending and receiving emails, finding information about goods and services, and online banking (Office of National Statistics, 2009). However, one of the most rapidly growing internet activities within the UK is OHI seeking (Office of National Statistics, 2009). UK national statistics suggest that, in 2009, around 42% (n=965) of individuals sought health information online, an increase of 23.5% on the previous year, and 55.6% on 2007 figures (Office of National Statistics, 2007, Office of National Statistics, 2008, Office of National Statistics, 2009). This data suggests that, within the UK, the internet is increasingly becoming an important source of health information for the general public, signifying the need for further research into how these individuals are operating. Several recent studies have already attempted to ascertain the manner in which the public look for health information online in an effort to understand the socially and politically relevant phenomenon (Pew Internet, 2000, Eysenbach and Kohler, 2002, Pew Internet, 2003, Sillence et al., 2007, Harris Interactive, 2008, Pew Internet, 2009).

Large-scale research

Currently, the majority of large-scale research into the OHI-seeking experience has been conducted within the United States (US) (Pew Internet, 2000, Pew Internet, 2003, Harris Interactive, 2008, Pew Internet, 2009). Although the US health service differs significantly from that of the UK (Schoen et al., 2005), this data provides potentially indicative research from a fellow western nation that has experienced advanced industrialisation. The Pew Internet and American Life study (2000) provides an early example of a large-scale social survey of US citizens regarding their online behaviours in terms of OHI seeking. Findings from this study suggested that the typical online health seeker is a sporadic user of OHI (Pew Internet, 2000). More recent research has specified that 81% (n=1825) of internet users go online and do something health related less often than once a week, confirming that few people are engaged in performing health-related searches on a daily or weekly basis (Pew

Internet, 2009). Further large-scale research from the US supports these findings, signifying that only 25% (n=253) of internet users stated that they used the internet to look for health information on a regular basis, with 30% (n=303) stating that they used it sometimes, and 17% (n=171) hardly ever (Harris Interactive, 2008). These large-scale studies also provide evidence of individuals' motivations for OHI seeking. Specifically, the 2009 Pew Internet survey demonstrates that 49% (n=1104) of adults went online to get information about a specific disease or medical problem, 41% (n=924) used the internet to research a treatment or procedure, 33% (n=743) used it to research over the counter drugs, and 26% (n=586) went online to look at alternative treatments or medicines (Pew Internet, 2009).

Search & appraisal

There is a limited body of research available that considers how OHI seekers search for and appraise OHI (Eysenbach and Kohler, 2002, Sillence et al., 2007). Findings from these relatively rare studies suggest that individuals who engage in OHI seeking are generally careful appraisers of OHI, and despite an often suboptimal search technique are able to locate OHI reasonably effectively (Eysenbach and Kohler, 2002, Sillence et al., 2007). The large-scale US research specified that between 65% (n=657) (Harris Interactive, 2008) and 81% (n=10328) (Pew Internet, 2000) of OHI seekers located health information by using a search engine, with 24% (n=242) locating it through health portals, and 11% (n=111) through specific health-related websites (Harris Interactive, 2008).

Conclusion

The above demonstrates some of the limited research that has been conducted in terms of how individuals seek health information online. As previously mentioned, in order to assess this behaviour it is currently necessary to turn to the US, where significantly more large-scale research is available. However, differences in the US and UK health systems may contribute to variations in OHI usage and self-care in general. Recent research comparing patient experience within different countries has demonstrated that US patients with chronic health conditions are far less likely to visit health professionals when they are unwell due to the financial burden of health care within the US system (Schoen et al., 2005). Due to these differences and the emerging prevalence of this social phenomenon within the UK (Office of National Statistics,

2009), additional research is needed to consider how UK individuals operate as OHI seekers.

In addition to considering the potential differences between US and UK samples, it is also important to consider a critical appraisal of these large-scale studies. The three reports cited by Pew (2000, 2003 and 2009) all present data from large scale US telephone surveys. Although telephone surveys are a popular mode of large-scale data collection (Frickler et al., 2005), they are also the subject of criticism due to potential communicative and practical obstacles. These obstacles introduce a level of inevitable bias/error into the findings from opinion polls. In order to minimise bias, and produce data which can be generalised in terms of the US population, Pew have utilised a number of specific measures. Firstly, all three studies utilised random telephone number generation techniques that were regionally distributed to minimise sampling error. Secondly, 10 attempts were made to each household within the samples to maximise response rate. Finally demographic weighting parameters derived from a US national census were adopted in order to ensure that the sample was representative. Similarly, the Harris (2008) survey also used random number assignment and demographic weighting techniques to ensure a representative sample. Despite these measures it could be argued that these studies are subject potential error due to the nature of the methodological approach only providing access to individuals with a home telephone. Therefore the literature demonstrates a need for further large scale research that represents the whole population.

The increased popularity of the internet as a health information source demonstrates that the general public are awakening to the potential benefits to seeking information relating to their health online. The Pew Internet and American Life study (2000) initially noted the internet's powerful influence on health seekers. Within this study, 48% (n=6120) of respondents felt that the advice they had located online had improved the way they cared for themselves, and 55% (n=7013) explained that access to OHI had improved the way they got medical and health information (Pew Internet, 2000). More recent findings have demonstrated that 60% (n=1352) of OHI seekers feel that they, or someone they know, have been helped by medical advice from the internet, an increase of 93.5% since the 2006 findings (Pew Internet, 2009). This positive powerful impact demonstrates the potentially beneficial nature of the internet

as a health information source for the general public. A further survey demonstrated similar positive responses from seekers, with 89% (n=899) stating that they felt their OHI-seeking experiences were successful (Harris Interactive, 2008).

The Potential of Online Health Information

As the demand for OHI increases, so does the volume of websites offering patient health information. Currently, the general public has access to a diverse variety of health websites, ranging from those produced by governmental and institutional sources (e.g. NHS Direct and NHS Choices), to sites from non-profit organisations and charities (e.g. Cancer Research UK). OHI seekers also have access to a variety of health information websites from unreviewed sources, including sites produced by health and social care professionals and well-informed individuals, and information from more questionable sources such as companies with financial interests and information from less-knowledgeable sources.

In order to provide a simple typology of OHI, the key sources can be divided into two main categories: traditional static websites, and collaborative sources. Traditional static websites include government, charity, company and independent websites, as well as online encyclopaedias such as Britannica. Collaborative sources of OHI include discussion boards, social networking sites and groups, forums, blogs, wikis and podcasts or vodcasts. In recent times it has become commonplace for websites to incorporate a wider variety of OHI dissemination techniques in order to maximise the potential of different types on information sharing.

Comparison to other sources

OHI has great potential to educate and empower individuals by providing health information on general health and services, and supporting self-help and patient choice (Powell et al., 2003, Murray et al., 2005). Furthermore, health information websites have numerous benefits over traditional sources of health information; by offering the potential to increase access to health information for individuals living in remote locations or for underserved populations (US Department of Health and Human Services, 2002, Becker, 2004); and by providing a standard of higher volume, more individually tailored OHI (Cline and Haynes, 2001).

The widespread availability of health information online has the potential to allow individuals contact with an interminable volume of health-related information that can be accessed from their homes, workplaces and local public facilities such as libraries. Supposedly available to anyone, one of the major benefits of the internet is its ability to increase access to health information for individuals living in remote locations, who are underserved in terms of health information from traditional sources (Cline and Haynes, 2001), or have conditions preventing them from utilising traditional healthcare information services (US Department of Health and Human Services, 2002, Becker, 2004). Numerous studies have noted that individuals who live in remote locations have to travel greater distances to receive health care, are less likely to have access to healthcare services, visit healthcare professionals on a less regular basis and have lower health status than those living in more urban or suburban areas (Hartley, 2004, Chan et al., 2006, Jameson, 2006). OHI has the potential to bridge health information disparities by providing individuals in rural areas with greater equity in health information access. Although studies pertaining to the OHI-seeking experiences of individuals in rural areas are rare (Hale and Cotten, 2010), a recent study into how rural women obtain information relating to their health demonstrated that a significant number relied on health information websites as a source of health information (Wathen and Harris, 2007). An additional study of the influence of internet support programmes on chronically ill rural women reported that online intervention improved self-esteem, social support and empowerment (Hill et al., 2006). In addition to having the potential to inform individuals living in rural locations, the internet also has potentially positive implications for the significantly higher than average number of older adults who live with some form of disability, whose situation creates an additional barrier to accessing traditional forms of health information (US Department of Health and Human Services, 2002).

OHI has the capacity to provide individuals with personally tailored health information, anonymously, in a variety of different forms that is often more current than traditional sources such as printed books and journals (Robinson et al., 1998). It also offers the potential for health information to be disseminated to a large number of internet users quickly and relatively inexpensively (Ball and Lillis, 2001). The high volume of current OHI that allows for widespread dissemination of a range of services, enables health information seekers to select information based around their

individual health information requirements and literacy levels in a way that is convenient and relatively affordable (Ball and Lillis, 2001, Cline and Haynes, 2001). Specifically, research suggests that 93% (n=11858) of OHI seekers felt that it was extremely important to get health information at a time and place that is flexible to them, with a further 83% (n=10583) demonstrating the importance of getting more health information online than from other sources (Pew Internet, 2000). In addition, 80% (n=10201) noted the importance of being able to operate as a health information seeker within an anonymous space (Pew Internet, 2000), and 33% (n=165) of US adults described using the internet to obtain information about a sensitive topic that was difficult to talk about (Fox and Rainie, 2002).

As well as providing a number of potential benefits over traditional health information sources, the practice of seeking health information via the internet is also associated with a number of additional potential benefits to individuals. These benefits include increased self-efficacy, feelings of control and empowerment (Sharf, 1997, Murray et al., 2005, Bass et al., 2006), increased social support and channels of communication (Barrera et al., 2002, Murray et al., 2005, Hill et al., 2006, Wangberg et al., 2007), assistance in decision-making (Eysenbach and Jadad, 2001, Baker et al., 2003, Murray et al., 2003, Bass et al., 2006, Sillence et al., 2007, Kirschning and von Kardorff, 2008, Lau and Coiera, 2008), and improved discussions with health professionals (Murray et al., 2003, Kirschning and von Kardorff, 2008).

Numerous studies have demonstrated a relationship between OHI seeking and increased feelings of self-efficacy and empowerment (Sharf, 1997, Murray et al., 2005, Bass et al., 2006). Bandura (1994) defines self-efficacy as:

...people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes. (Bandura, 1994, p.71).

To reiterate, self-efficacy refers to individuals' belief in their ability to perform a specific task. Research into the experiences of newly diagnosed cancer patients shows that internet use is significantly associated with self-efficacy variables such as confidence in actively participating in treatment decisions, asking physicians questions and sharing feelings of concern (Bass et al., 2006).

In terms of Bandura's model of self-efficacy, empowerment refers to a process whereby an individual's belief in their self-efficacy is enhanced (Conger and Kanungo, 1988). Additional research suggests that the increased volume of online health websites available to patients forces health professionals to discuss possible treatment options in more detail, leading to feelings of empowerment for patients (Sharf, 1997). Similarly, a 2006 US study on the impact of online interventions on the psychological status of chronically ill rural women (Hill et al., 2006) demonstrated that women in the online intervention group had significant positive correlation with empowerment compared with the control group.

Another potential benefit to OHI seekers that relates directly to self-efficacy is improved feelings of control. A recent study into the use of the internet for men and women with cancer demonstrated that 54% (n=304) of German participants felt that searching for OHI websites made them feel in better control of their chronic health conditions (Kirschning and von Kardorff, 2008). These findings are extremely pertinent because there is an extensive body of work linking sense of control with improved physical and psychological health (Rodin, 1986).

Patients with higher self-efficacy generally show more self-management behaviours, which in turn lead to improved quality of life (Weng et al., 2009). Quality of life is demonstrated through the physical, psychological and social domains of health, and appears to be influenced by factors such as personal experience, beliefs, expectations and perceptions (Burra et al., 2007). The improvement of individuals' quality of life is a critical goal of treatment for chronic populations, for whom medicine's power to cure is limited (Lehman et al., 1993).

Research has shown that seeking OHI and utilising online support applications can also lead to an increase in levels of social support (Barrera et al., 2002, Eysenbach et

al., 2004, Murray et al., 2005, Hill et al., 2006). The concept of social support is based on the work of Weiss (1969) and includes the provision of intimacy, facilitation of social integration, opportunity for nurturing behaviour, reassurance of self-worth and availability of informational assistance (Weiss, 1969). In terms of health, social support can help minimise the negative effects of damaging life events and improve overall wellbeing (Pollack, 1986), and can positively influence self-management of chronic illness (Gallant, 2003). Numerous studies have looked into how online health initiatives can help promote feelings of social support (Barrera et al., 2002, Eysenbach et al., 2004, Murray et al., 2005, Hill et al., 2006). An US experimental trial of a number of different approaches for supporting diabetes self-management showed that individuals who participated in internet-based social support interventions showed significant increases in the perceived availability of social support (Barrera et al., 2002). Similar results were reported by Hill et al. (2006) who conducted a study to help examine the effects of an online intervention on measures of psychosocial health, including social support in chronically ill rural women. They saw a significant positive association between involvement in the online support programme and social support as well as empowerment and self-esteem. In a more recent study into relationships between internet use and social support relating to health care in seven different European countries (Wangberg et al., 2007), internet users who had used the web for health purposes were compared with internet users who had no experience of this. Results demonstrated that internet use was found to be more closely related to social support than the use of other media.

Confirming these findings, a 2005 systematic review of online and offline interactive health communication applications for people with chronic disease demonstrated that such applications had a significant positive effect on social support, as well as health knowledge, health behaviours and clinical outcomes (Murray et al., 2005). Previously in 2004 an additional systematic review of the effects of health-related virtual communities and electronic support groups suggested that no robust evidence existed of a significant relationship between virtual communities and online support groups and social support, partly because the majority of online communities have been evaluated alongside more complex interventions or with the involvement of professionals (Eysenbach et al., 2004). However, it is important to consider that these reviews are not directly comparable due to the differences in study selection criteria.

Whilst Murray et al. included studies assessing the effect of offline and online interactive computer applications that involved communication, Eysenbach et al. looked at electronic support groups, only around a sixth of which were ‘pure’ peer to peer (Murray et al., 2005).

The potential of Web 2.0 applications

In addition to the aforementioned online applications providing the potential for increased social support for patients, the emergence of new, more social web technologies has implications for developing the range of information available online and, above all, improving social communication between patients and among patients and professionals. The ‘second incarnation’ of the internet has been hailed as Web 2.0 (O’Reilly, 2005). During his attempt to clarify the term, O’Reilly admits that there is still huge disagreement about just what Web 2.0 means ‘with some people decrying it as a meaningless marketing buzzword, and others accepting it as the new conventional wisdom’ (O’Reilly, 2005 p.1) . The following table was included to help clarify what he originally meant by Web 2.0:

Web 1.0		Web 2.0
DoubleClick	→	Google AdSense
Ofoto	→	Flickr
Akamai	→	BitTorrent
mp3.com	→	Napster
Britannica Online	→	Wikipedia
personal websites	→	blogging
evite	→	upcoming.org and EVDB
domain name speculation	→	search engine optimisation
page views	→	cost per click
screen scraping	→	web services
publishing	→	Participation
content management systems	→	wikis
directories (taxonomy)	→	tagging (‘folksonomy’)
stickiness	→	Syndication

Table 2. The differences between Web 1.0 and Web 2.0.

Adapted from <http://oreilly.com/web2/archive/what-is-web-20.html>

Table 2 demonstrates that Web 2.0 is an umbrella term that refers to new web technologies and services that encourage lay users to contribute to content creation. The theory is that, by encouraging users to generate and publish web content, this will enable a form of 'collective intelligence' that will encourage more democratic use (Boulos and Wheeler, 2007). Although some forms of social web technology such as discussion boards have been around for years, many researchers believe that Web 2.0 still has implications for the future of health care by further enhancing the connection between patients, clinicians and health information (Kamel Boulos and Wheeler, 2007, Murray, 2008). The use of blogs, podcasts and wikis can help to both communicate health information and increase social support by providing a potentially anonymous space within which online interaction can take place. It also allows the information seeker to rapidly become the information provider, and to share healthcare knowledge and experiences quickly and easily.

As well as the internet having the potential to increase the wellbeing of OHI seekers by increasing empowerment, self-efficacy and perceived social support, it also has the potential to provide additional benefits to OHI seekers in terms of increasing individuals' sense of agency. Increased agency can lead to individuals taking a more active role in their health care, can contribute towards healthcare decision-making, and can help promote discussions between patients and health professionals.

Improving decision-making

Health information websites are now recognised as an important source of information that contributes towards individuals' health-related decision-making (Pew Internet, 2000, Eysenbach and Jadad, 2001, Baker et al., 2003, Murray et al., 2003, Bass et al., 2006, Sillence et al., 2007, Kirschning and von Kardorff, 2008, Lau and Coiera, 2008). Early research demonstrated that around 70% (n=8926) of OHI seekers felt that the health information they had found online had previously helped them make a decision about how to treat an illness or condition, with 18% (n=2295) reporting to going online to self-diagnose a condition without discussing it with a doctor (Pew Internet, 2000). More recently, it was suggested that a smaller, but still significant, percentage (60% (n=1352)) of OHI seekers had used OHI to make

decisions about their health and treatment regimes (Pew Internet, 2009). Similar findings were demonstrated by research into the experiences of newly diagnosed cancer patients (Bass et al., 2006). This study demonstrated that respondents perceived the internet as a powerful tool, both for acquiring information and for enhancing confidence to make informed decisions about their health care. Furthermore, a US survey of the perceived effects of internet use on healthcare understanding and decision-making demonstrated that 48% of patients with chronic health conditions (n=999) and 67% (n=1797) of the control group agreed or strongly agreed that using the internet or email improved their understanding of symptoms, treatment or conditions in which they were interested (Baker et al., 2003). In addition, results showed that 32% (n=1524) of all participants had used the internet to make decisions relating to their health care. A further study into how patients evaluate and make use of OHI (Sillence et al., 2007) looked at how 15 women facing decisions relating to the menopause and hormone replacement therapy utilised the internet. Results demonstrated that most women felt that the internet played an important role in the early stages of decision-making, with some noting specifically that the internet could be an extremely useful first port of call when faced with a new health scare. Sillence et al. (2007) state that people should further recognise that patient decision-making is influenced by the internet, and should understand that the consultation process is increasingly a forum where patients want to test out their internet-informed hypotheses about their own treatment regimes.

Improving discussions

Research has also demonstrated that seeking health information via the internet can lead to improved discussions with health professionals (HON, 2002, Murray et al., 2003, Kirschning and von Kardorff, 2008). The 2002 Health on the Net report demonstrated that a large minority of European health seekers (45%) said that their OHI searches have made interactions with physicians more positive (HON, 2002). Similarly, a European online questionnaire looking into the use of the internet for men and women with cancer revealed that 52.5% (n=296) of respondents felt that OHI allows for more constructive shaping of consultations with doctors (Kirschning and von Kardorff, 2008). These studies suggest that OHI seeking has a potential impact on patients' ability to discuss their health care, as well as having a positive impact on decision-making. Results from a telephone survey conducted with 1,050 members of

the American public demonstrated overwhelmingly positive responses, with 97% (n=1018) of respondents stating that they believed OHI gave patients more confidence to talk to a physician about their concerns (Murray et al., 2003). The same study also found that 95% (n=997) of respondents felt that OHI seeking improved patients' understanding of their conditions, and 85% (n=893) felt that it encouraged patients to take advice from health professionals. When asked about the effect of OHI seeking personally, participants were also very positive, with 74% (n=777) stating OHI had been beneficial to their own decision-making ability. Furthermore, 86% (n=903) said that it had helped them understand their problem, and 69% (n=705) said the information helped them take better care of their health.

Reducing health service utilisation

In addition to research demonstrating the potential benefits of OHI seeking from the patients' perspective, further studies suggest that the internet has the additional potential to have an effect on the reduction of health service utilisation (Pew Internet, 2009). Recent research has demonstrated that a substantial percentage of respondents (38%) felt that OHI affected their decision regarding whether to visit a health professional (Pew Internet, 2009). This percentage is slightly higher than earlier research, which discovered that 28% (n=140) of respondents felt that OHI affected their decision about whether to visit a health professional or not (Fox and Rainie, 2002). However this same earlier study also demonstrated that only a very small percentage of OHI seekers used the internet to get medical advice instead of visiting a health professional: 2% (n=10) sought information for themselves and 3% (n=15) sought information on behalf of someone else (Fox and Rainie, 2002). Furthermore, an additional study has found that the internet had little impact on measurable healthcare utilisation, with 94% (n=4431) of individuals reporting that internet use had no effect on the number of physician visits that they had made, and 93% (n=4383) stating that it had no effect on the amount of telephone contact with health professionals they had received (Baker et al., 2003).

Additional research has linked involvement in internet education programmes with health service utilisation (Runge et al., 2006). A 2006 study of asthma patients in Germany showed that patients involved in an internet-based education programme were less likely to utilise health services than a control group. The study also looked

at health service utilisation for traditional non-internet based programmes, and found a similar significant negative effect on health service utilisation. However, they also discovered that the internet programme was a more cost-effective means of informing and educating patients (Runge et al., 2006).

Recent themes within UK health policy discuss individuals taking more responsibility for their own health care, the emergence of ‘expert patients’ and the development of a partnership relationship between patient and caregiver (Department of Health, 1998, Department of Health, 2000, Department of Health, 2004, Department of Health, 2005, Darzi, 2008, Department of Health, 2009). For these themes to be recognised, and for the modernisation of the National Health Service (NHS) to occur, individuals must have access to the information that they require to make informed decisions about their health care. The preceding discussion demonstrates that the internet has the potential to inform individuals, thereby improving quality of life, and to develop the role of the patient in health care (Gray and Rutter, 2002, Powell et al., 2003) by promoting feelings of empowerment and self-management behaviour such as decision-making and engagement in two-way discussions with health professionals. Despite the potential for the internet to have a positive effect on the lives of OHI seekers, there are also numerous studies which suggest that OHI is a potentially hazardous source of health information, and that barriers frequently exist between OHI seekers and this vast wealth of information.

The Barriers to Online Health Information

The aforementioned themes of modernisation that have featured heavily within UK public health policy over the past decade suggest that when provided with accurate information, patients will be equipped to make informed decisions about their own health. However, this claim is based on the assumption that the public has the ability to locate accurate information relating to their condition of their own accord. The reality is that, while the internet may offer a world of valuable healthcare knowledge and communication technologies with endless possibilities for the future of health care, it may also provide a maze of information of varying quality that requires high levels of general, health and information technology (IT) literacy to navigate. The following will provide a discussion of the potential barriers to the public locating

useful and relevant OHI, starting with a discussion of the quality debate in OHI seeking.

Quality

The internet is characterised by the unregulated, uncontrolled and unmonitored publishing of information (Marra et al., 1996, Cline and Haynes, 2001). The potential for free exchange of ideas, open communication and the right to differ in opinion are values frequently referred to as positive features of the internet as opposed to more traditional information sources. However, in terms of OHI, research suggests that the open nature of the internet and heightened demand for health information online has led to the development of significant volumes of unchecked, unstructured and unregulated information available to the general public (Mandl et al., 2001). In addition, there is currently no universally approved mechanism for ensuring the accuracy, currency and completeness of OHI available to the general public (Hersey et al., 1997, Eysenbach and Jadad, 2001), which means there is no control exercised over who can publish information as a self-appointed health expert. Concerns about the quality of OHI have also been noted by OHI seekers (HON, 1999, Pew Internet, 2000, HON, 2002). Early findings demonstrated that between 71% (n=2326) and 86% (n=10966) of OHI seekers were concerned about getting health information from an unreliable source online (HON, 1999, Pew Internet, 2000). Further research indicated that patients felt that accuracy of OHI and trustworthiness of information were the two most critical issues facing medical content on the internet (HON, 2002). Despite these findings, recent research has demonstrated that the overwhelming majority of OHI seekers believe that the health information they obtain via the internet is reliable (Harris Interactive, 2008). These contradictory findings highlight a need for additional research into patients' beliefs regarding the quality of OHI.

Numerous research studies support the belief that the quality of OHI needs to improve (Impicciatore et al., 1997, Berland et al., 2001). An early study into the reliability of sites containing information relating to the home management of children with fevers found that only four of the 41 websites that were considered adhered closely with the primary recommended guidelines that the information was checked against (Impicciatore et al., 1997). Less extreme findings were presented by a 2001 study into the accessibility, quality and readability of English and Spanish-language websites

(Berland et al., 2001). Results from the English-language websites reviewed demonstrated that the mean percentage of covered clinical elements for which the text was completely correct ranged from 75% to 91%, depending on which chronic condition the information related to. Furthermore, in 2002, Eysenbach et al. conducted a systematic review of empirical studies assessing the quality of health information for OHI seekers (Eysenbach et al., 2002). Results demonstrated that the majority of studies (70% (n=55)) concluded that quality of health information was a problem on the internet, compared with 21% (n=17) who remained more neutral and 7% (n=6) who were positive about health information quality online.

Although there are large differences in the results from studies investigating OHI quality, research has suggested that even a low prevalence of poor quality OHI is potentially extremely harmful to vulnerable OHI seekers (Biermann et al., 1999, Eysenbach and Jadad, 2001). In an evaluation of cancer information on the internet, Biermann et al. found that only four out of 70 cases (6%) of OHI contained erroneous information. However, they concluded that, despite the low prevalence of inaccurate information, the potential effects that such postings may have on vulnerable patients are of serious concern (Biermann et al., 1999). Eysenbach and Jadad (2001) display similar trepidation by stating that misinformation can lead to patients with life-threatening conditions losing trust in their healthcare provider and taking actions that undermine the effectiveness of their treatment. They also add that vulnerable individuals may also be victimised by biased or incomplete information from those with a financial interest in the information that they provide (Eysenbach and Jadad, 2001).

Although there is continuing concern regarding the quality of health information online, OHI seekers are progressively being confronted with more tools to assist in the cross-checking of OHI for quality (Cline and Haynes, 2001). Several organisations have developed criteria to guide and evaluate health-related website content (e.g. HON code, Discern, American Medical Association). However, these tools have been the subject of much criticism due to their reliance on voluntary self-assessments by authors and concerns about their implications for consumer navigation (Bernstam et al., 2008). In 2008, Bernstam et al. conducted a study into the effectiveness of the commonly cited website quality assessment criteria used within

various assessment tools. They discovered that these criteria were unable to help respondents identify inaccurate OHI (Bernstam et al., 2008). Despite this, the study also suggested that most breast cancer information that OHI seekers encountered is accurate (94.8% (n=411)) (Bernstam et al., 2008). Similar, yet more extreme, findings were presented in a 2006 study into the prevalence of misleading statements in messages posted on online cancer support boards (Esquivel, 2006). This research demonstrated that only 10 out of the 4,600 postings (0.22%) that were assessed contained false or misleading statements. In addition, of the 10 poor quality statements, seven were identified by patients and corrected in an average of 4.5 hours.

The aforementioned findings confirm that the scale of the quality problem and the potential effects on OHI seekers are still unclear (Eysenbach et al., 2002). However, numerous studies have stated that, in spite of the potentially erroneous OHI available, before we conclude that it is inadequate, we must compare it with other more traditional sources of health information (McLeod, 1998, Eysenbach et al., 2002, Ferguson, 2002). In 1998, McLeod stated that the internet suffers from error and inaccuracy no more than many other informal sources of health information, including acquaintances, pamphlets and press articles (McLeod, 1998). Similar sentiments were echoed by Ferguson in 2002 who stated that the quality of OHI needs to be compared with that which a doctor tells the patient in a typical consultation before we can conclude that the quality is insufficient (Ferguson, 2002). Eysenbach et al. 2002 add that many of the shortcomings detected as being likely are not specific to the web and are present in other media (Eysenbach et al., 2002). They provide the example from Biermann et al. who demonstrate through their evaluation of cancer information that two of the four erroneous information elements found on 65 websites were also located within the online version of the Encyclopaedia Britannica, and were therefore also likely to be included within the offline version (Biermann et al., 1999). It could be argued that, rather than OHI being the beginning of an epidemic of misinformation, it is nothing more than a variation of what is endemic (Coiera, 1996, Coiera, 1998, Eysenbach et al., 2002), and that inaccuracies appear consistently throughout all media sources and are not uniquely online. It may also be true that the quality of OHI is given so much more emphasis due the inappropriate criteria used to judge it (Eysenbach et al., 2002, Bernstam et al., 2008). For example, traditional quality criticisms used for other media include lack of completeness, while web-based

information is part of a universe of information (Eysenbach et al., 2002). The development of web-specific criteria may make quality assessments more valid for OHI and so provide a more comprehensive picture of the scope of the quality issue.

The progress of new web technologies presents fresh controversies in regard to the OHI quality debate. The emergence of Web 2.0 has facilitated many new online activities that could not be achieved by the previous incarnation (Web 1.0). The use of blogs, podcasts and wikis can help to both communicate health information and increase social support by providing a potentially anonymous space within which online interaction can take place. It also allows the information seeker to rapidly become the information provider and to share healthcare knowledge and experiences quickly and easily. This benefit of Web 2.0 technology may also be seen as a limitation when discussing information quality. For example, although health-related wikis and blogs are an excellent way to share health information, their content can be added and edited by anyone, with a significant number being fuelled by lay users often with no professional experience of the health topic they are writing about (Barsky and Giustini, 2007). This can make it problematic to gauge the reliability and accuracy of such sources (Boulos et al., 2006, Kamel Boulos and Wheeler, 2007).

Conversely, it has also been suggested that the development and increased usage of Web 2.0 applications may help improve the overall quality of health information that is provided to patients. The concept of 'Darwikinism' describes the evolutionary selection process that occurs within wikis when 'unfit' sentences and sections are ruthlessly culled and voted against but when considered 'fit' are developed, resulting in the evolution of higher quality, more relevant content (Boulos et al., 2006). These notions are also adopted by collaborative filtering systems. Such systems can produce personal recommendations by computing the similarity between individuals' preferences and the preferences of others, and can share judgements of quality that may assist OHI seekers in locating accurate information.

The preceding demonstrates that further research is needed in order for researchers to fully understand the extent of the OHI quality issue, as well as the effect of poor-quality OHI on seekers and the consequences of emerging web technologies on the quality debate. However, it is important to note that, as well as considering the overall

quality of OHI, it is vital to reflect on individuals' ability to search for and locate quality information, and the additional barriers that may prevent them from doing so.

Despite the large volume of OHI of varying quality made available by the internet, relatively few studies have been conducted to assess the capabilities of OHI seekers in effectively searching for and appraising OHI (Eysenbach and Kohler, 2002, Sillence et al., 2007). OHI seekers are faced with a number of potential obstacles in searching for and appraising OHI, such as information overload, searching difficulties, disorganised information and information that lacks user friendliness (Cline and Haynes, 2001).

Search and appraisal skills

In order to assess patients' search and appraisal skills, Eysenbach and Kohler utilised lab sessions where participants were given a series of health questions and were observed whilst they retrieved the answers using the internet (Eysenbach and Kohler, 2002). They found that none of their participants used medical portals or the sites of medical societies or libraries as a starting point; participants were more likely to use search engines instead. The authors also stated that search strategies used by participants were somewhat suboptimal, with few using combinations of words and only one using explicit Boolean operators. In addition, participants explicitly stated the importance of website credibility and explained that they looked for source of information as well as the presentation. In practice, however, they discovered that no participants checked the 'about us' section of the websites or the disclaimers/disclosure sections. Despite these concerning findings, the study continued to report that participants were able to successfully locate the information that they required by trying various search terms, exploring the first few emerging pages and refining their searching strategy accordingly (Eysenbach and Kohler, 2002). These findings were consistent with a more recent study that demonstrated that, once participants had made the rapid selection of sites that they believed to be of interest, they became careful evaluators of the OHI (Sillence et al., 2007). The limited research available on this important topic suggests that, although OHI seekers' searching behaviour may be suboptimal and not comply with traditional quality searching strategies (Eysenbach and Kohler, 2002), they were able to search and appraise OHI effectively (Eysenbach et al., 2002, Sillence et al., 2007). Although these findings suggest that in these cases

search and appraisal skills were not a specific barrier to locating relevant and useful OHI, further research needs to be conducted to ascertain the appropriateness of search and appraisal techniques and whether these do in fact act as a barrier to OHI for patients.

Literacy

Research has also suggested that additional barriers may have an effect on OHI seekers' abilities to effectively search and appraise OHI; these include general, health, and IT literacy, as well as various demographic factors.

Literacy is the ability to identify, understand, interpret, create, communicate, and compute using printed and written materials associated with varying context. Literacy involves a continuum of learning and enabling individuals to achieve their goals, to develop their knowledge and potential and to participate fully in their community and wider society. (UNESCO Educational Sector, 2004, p.13).

The aforementioned demonstrates that the focus of the definition of literacy is an individual's ability to comprehend information that it presented in the printed or written format (Anton and Nelson, 2006). Successful use of the internet as a health information source depends on several different types of literacy. General, health and IT literacy along with language all act as barriers to individuals' abilities to locate and understand OHI (Cline and Haynes, 2001).

If an individual has poor levels of literacy generally, they are unlikely to be able to comprehend information that is presented online. This is extremely pertinent in the case of OHI because research has shown that health websites are generally presented for an audience with high standards of general literacy (Berland et al., 2001, Birru et al., 2004). In a 2001 study of the readability of English and Spanish health information websites, it was reported that all the websites considered for the study required a high-school level or greater reading ability in order to understand them effectively (Berland et al., 2001). Similar findings were confirmed within an observational study into the information-seeking behaviour of low literacy adults, which demonstrated that within this study most of the commercial health websites

studied were in the 9th–12th grade (14–18 yrs) readability range, much higher than what is recommended when providing information to a public audience (Birru et al., 2004).

Without a good general standard of literacy, patients are unable to maintain suitable health literacy levels in order to understand the health information that is available online (Anton and Nelson, 2006). Health information literacy relates to the skills that an individual requires to identify potential sources of useful health information, to retrieve and assess information, and to use it to make constructive health decisions that could potentially lead to positive health outcomes. Low levels of health literacy can frequently impair individuals' abilities to understand health messages (Eysenbach and Jadad, 2001) by imposing limits on their cognitive and linguistic potential. This has a significant influence on an individual's ability to navigate within a literate environment such as the internet (Baker et al., 1996, Chu et al., 2009).

Computer or IT literacy is also a major barrier to people being able to benefit from OHI, with many individuals not knowing how to use, or being scared of using, computers and the internet (Cline and Haynes, 2001). Individuals who lack the skills and training to be fluent with IT are unlikely to be able to benefit from the potential of health information presented online. However, the IT skills that individuals are developing through education and the increasing popularisation of the internet may mean that the scale of this issue gradually decreases.

As well as the above forms of literacy, language also acts as a barrier to OHI seeking (Cline and Haynes, 2001, Crystal, 2003, Anton and Nelson, 2006, Khechine et al., 2008). People unable to speak, read or understand English are disadvantaged because it is the predominant language online (Crystal, 2003, Khechine et al., 2008). In his 2003 book *English as a Global Language*, Crystal suggests that there is a serious possibility that if you cannot understand the English language, you will be left unable to take advantage of the intellectual power the internet provides, which could lead to people being divided into two classes: the information literate and the illiterate (Crystal, 2003). This theory is referred to as the 'digital divide' (Brodie et al., 2000). The term 'digital divide' is also used to refer to disparities in computer access for

individuals because of various demographic factors such as age, education, race and income.

Demographic factors

Numerous research projects and national surveys have suggested that age is a key factor that discriminates between online and offline information seekers, with general and health-related internet usage being less frequent within older populations (Cotten and Gupta, 2004, Office of National Statistics, 2009). These findings are extremely pertinent because access to health information has the potential to be even more significant for older adults as health problems tend to increase with age (Nussbaum and Coupland, 2004). In 2004, Cotton and Gupta presented data from a subsample of individuals from a 2000 General Social Survey in the US. Their findings demonstrated that the mean age for the non-users of OHI was 11 years older than for an OHI seeking group (Cotten and Gupta, 2004). Despite these significant findings, they also suggested that, given the finding in recent research that older adults are increasingly using the internet (Fox, 2001, Office of National Statistics, 2009), the size of this divide may decline over time. Specifically, the recent 2009 UK National Statistics report demonstrated that, although there was a significant negative correlation between age and internet usage, the largest increase in the proportion of those accessing the internet was in the older age group (65+ years) (Office of National Statistics, 2009). Findings showed that access by those aged 65+ years increased proportionally by 15%, compared with an increase of only 3% for the 16–24 years age group. These results suggest that, although research points to a digital divide existing in terms age within the phenomenon of OHI seeking, the scale of this problem may be reducing significantly.

Studies into the digital divide have also cited that more educated individuals are more likely to use the internet in general as well as for health seeking purposes (Brodie et al., 2000, Cotten and Gupta, 2004), placing education as a potential discriminating factor in OHI seeking. Brodie et al. (2000) report seeing a digital divide in educational levels within their research, identifying that more highly educated individuals were more likely to use computers to look for OHI (Brodie et al., 2000). Specifically, they found that 39% (n=434) of participants with a college qualification or higher had used a computer at home to get health or medical information,

compared with just 22% (n=247) (of those with a high school diploma or less. These early findings suggest that further research should be conducted to understand which aspects of higher education lead to increased OHI usage, and whether the size of the gap reduced once other factors were controlled such as age, income and race.

Over previous years, race has also been considered a potential barrier to individuals seeking health information online (Brodie et al., 2000, Lorence et al., 2006). Early studies demonstrated that white respondents were more likely to engage in OHI seeking than their Hispanic (Lorence et al., 2006) and black counterparts (Brodie et al., 2000, Ross et al., 2000). However, this early research also demonstrated that much of this effect disappeared when income was controlled for (Brodie et al., 2000). Similarly, research has demonstrated that the wealthiest 10% of households are more than seven times more likely to use the internet compared with the poorest 10% in the UK (Nettleton et al., 2004). Explanations for this trend could be that economically disadvantaged individuals are not able to fully utilise media resources such as the internet due to limited access and lower reading levels (Cotten and Gupta, 2004). However, the reduced cost of high-speed internet has reduced the potential for socio-economic disparities in internet access within developed countries. These changes have been reflected within more recent research that suggests that the digital race divide is being bridged (Cotten and Jelenewicz, 2006).

The preceding section demonstrates that while the internet could be a powerful medium for the democratisation of health care, numerous potential barriers prevent equality. These obstacles have important implications in regards to the modernisation of health services and patient involvement in health care because these reforms rely on all individuals having access to the same high-quality OHI. Unless the existing disparities are addressed and producers of OHI consider their audience in terms of literacy and educational levels, there will continue to be a divide between those who have access to the wealth of health information online, and those who have not. It is important to consider, however, that these are not the only factors that inhibit the emergence of a patient-focused healthcare system. These changes also rely on the cooperation of health professionals and lay individuals in order to be effectively made.

The Role of Others

It is imperative to consider that the process of OHI seeking is not performed within a social vacuum (Pew Internet, 2009). In order for patients to effectively seek, evaluate and utilise health information online, they rely on interactions and the support of others such as family, friends and peers, as well as health professionals. Without the support of these individuals, the emergence of 'expert patients' and the development of partnership relationships between patients and providers are seriously inhibited. In addition, the popularity of email as a web-based communication tool, alongside the development of 'social web' technologies, has led to the interactivity of the internet potentially having an even more profound impact on health and health care in terms of its implications for communication and information sharing. Despite this potential, the road to the modernisation of the patient–practitioner relationship through the emergence of information-enabled patients is faced with obstacles in terms of those who are unhappy or unwilling to make the necessary changes.

Health care professionals

The traditional 'paternalistic' model of health care described as endemic within the NHS (Coulter, 1999) regards physicians and health professionals as experts, with patients offering very little to the table apart from their illness (Bodenheimer et al., 2002). This approach establishes and promotes an unhealthy dependency on health professionals to provide information and for patients to comply with it. In line with recent UK health policy, the internet is changing the balance of knowledge between healthcare professionals and the public, by empowering patients to become more involved in their health and healthcare decision-making (Powell et al., 2003). This approach embraces the components of collaborative care and self-management education in order to ensure individuals are informed to the extent that they can play an active role in decision-making and self-management of chronic conditions. Table 3 discusses the features involved with the traditional paternalistic model and suggests a modern partnership model of health care.

Feature	Traditional Paternalistic Model	Modern Partnership Approach
Relationship between patient and professional	Professionals – autonomous experts Patients – passive receivers	Shared expertise Professionals – experts about the disease Patients – active experts about their lives
Principal caregiver and problem solver who is responsible for outcomes	Professional	Shared responsibility between patients and professionals
Expected outcome	Compliance with instructions. Non-compliance is a personal deficit of the patient	The patient sets goals and the professional helps the patient make informed choices. Lack of goal achievement is solved by adapting strategies
How is behaviour changed?	External motivation	Internal motivation. Patients gain understanding and confidence to accomplish new behaviours
How are problems identified?	By the professional, e.g. changing unhealthy behaviours	By the patient, e.g. pain or inability to function; and by the professional
How are problems solved?	Professionals solve problems on behalf of patients	Professionals assist patients in problem solving by teaching them the necessary skills

Table 3. Comparison of the paternalistic and partnership models of health care.

Adapted from (Bodenheimer et al., 2002).

The idea to radically reorganise relationships within the healthcare system is based on the idea that patients and practitioners each have complementary knowledge that can be utilised to manage illness successfully and can help facilitate informed joint decisions regarding patients' health and treatment regimes. However, this approach operates under the assumption that patients and practitioners are each willing to adopt new roles within the healthcare interaction. Currently, very little is known about patients' readiness to adopt this powerful role within their health and treatment regimes, or about their willingness use the internet and other information sources to gather a wealth of health information (Coulter, 1999). In one of the rare studies that considers patient preferences, results demonstrated that many patients do not actually wish to take more responsibility for their health care and are happy to trust their GPs and leave decisions to them (Henwood et al., 2003). Further research specifically demonstrated that 52% (n=1438) of adults preferred to leave healthcare decisions to professionals (Levinson et al., 2005).

Despite these findings, numerous studies show that patients are demonstrating an intention to operate in partnership by regularly taking health information retrieved

electronically into the primary care consultation (Neff, 1999, Wilson, 1999, Murray et al., 2003, Harris Interactive, 2008). A 2003 US telephone survey established that 50% (n=525) of participants who had located OHI relating to their own health had taken the information into the consultation with health professionals (Murray et al., 2003). Similar findings were demonstrated in a more recent survey which reported that just under half (47%) (n=475) of OHI seekers had discussed the information that they located online with health professionals (Harris Interactive, 2008). In addition, participants also demonstrated that the main reason for sharing this information with a health professional was to ask their opinion about it (71% (n=746)) (Murray et al., 2003). Within this study, patients perceived the professionals as reacting positively in 67% (n=704) of cases, neutrally in 27% (n=284) and negatively in only 7% (n=74) of cases.

Despite the above research suggesting that health professionals react positively to OHI sharing behaviour, further studies have demonstrated that practitioners do not always consistently show this level of enthusiasm (Elwyn et al., 1999, Wilson, 1999, Henwood et al., 2003). The reversed information power balance motivated by this sharing culture brings conflict to the traditional paternalistic hegemony associated with primary care. It is therefore unsurprising that this behaviour has encountered some hostility from primary caregivers (Reents and Miller, 1998, Eysenbach and Alejandro, 2001). Despite the reported benefits of the patient bringing printouts into consultations, 'internet printout syndrome' – also referred to as 'cyberchondria' – has generally been portrayed as a time-consuming affliction as opposed to a useful communication technique (Powell et al., 2003). In a postal questionnaire among family doctors and practice nurses in Scotland, only 39% (n=117) of doctors and 31% (n=40) of nurses felt positive about patients using internet health resources. The remainder were indifferent, uncomfortable or unsure about patients operating in this manner (Wilson, 1999). In the same year, another UK study exploring the views of general practice registrars regarding the involvement of patients in decision-making demonstrated that registrars reported not being trained in the skills that they required to engage in partnership effectively (Elwyn et al., 1999). In addition, registrars demonstrated a wide range of opinions about involving patients in this way, from protective paternalism to potential rewards of a partnership approach. Furthermore, more recent research interviews conducted on 32 mid-life women within the UK

confirmed this apparent reluctance on the part of practitioners to engage in a partnership relationship with patients (Henwood et al., 2003). Results from this qualitative study demonstrated a number of examples where these women had become informed about aspects of their health care. However, when this information had been discussed with the health professional, they reported that their opinions were rapidly rejected or dismissed. More recently, a 2008 article in *The Times* newspaper entitled 'Ten ways to wind-up your GP' stated that the comment 'I've brought a printout off the internet' had a very high 'wind-up factor' for GPs (The Times Online). In the article, the anonymous GP states that they do not have the time to 'wade through' the information that is likely to be 'at best, misleading and, at worst, dangerous rubbish' (The Times Online p.1).

It is clear that the emergence of the expert patient and the adoption of the partnership approach may not emerge naturally within existing structures of health care (Henwood et al., 2003). Recommendations suggest that in order to assist their patients in effectively locating high-quality OHI and promote the emergence of 'expert patients', practitioners should recommend appropriate websites to patients, promote more search and evaluation strategies, and become involved in developing and implementing standards (Morahan-Martin, 2004).

Friends and family

As previously stated, OHI seeking does not occur within a social vacuum, with numerous studies considering the role of others within the OHI-seeking experience (Murray et al., 2003, Pew Internet, 2009). Early US research demonstrates that, while 53% (n=557) of individuals had found information relating to their own health online, 57% (n=599) had found information relating to the health of friends or relatives (Murray et al., 2003). Similarly, more recent research demonstrates that 52% (n=1172) of OHI inquiries are performed on behalf of someone else, and two-thirds of OHI seekers talk with another person about what they find online, most often a friend or spouse (Pew Internet, 2009). Data from this survey also indicated that 41% (n=924) of OHI seekers had read someone else's commentary on health and medical issues online via traditional websites and Web 2.0 applications such as blogs. In addition to these findings, results also showed that 24% (n=541) consulted ratings and reviews for providers and hospitals generated by other members of the public.

However, results also demonstrated that a small minority of participants were in fact contributing to health content (Pew Internet, 2009). These findings demonstrate the possibility of a strong social element to OHI seeking that could be developing with the emergence of social technologies and user-generated content. Future research is needed to identify how social interactions exist within OHI seeking, and to consider how the constantly expanding landscape of social technologies influences the social life of this popular activity.

Although there has been a rapid increase in the number of people using the internet to locate health information, we are far from a nation of expert patients with the ability to effectively search for and appraise OHI and consistently make informed decisions about our health care. The rapidity of technological advancement and changes in UK health policy has left little time for reflection on how people are operating as OHI seekers and on how they are finding, assessing and using OHI. In addition, relatively little reflection has been made regarding those individuals falling short of the digital divide and the obstacles that lie between these people and quality OHI. In order to progress to a partnership model of health care and to encourage the emergence of the 'expert patient', it is essential that more time is given to understanding patient preferences as well as how they are operating as information seekers, and to concluding how health professionals and others can work with them to assist future online information seeking.

Chapter 4. Methodological Approach

Introduction

The overarching objective of the research project was to develop greater insight into the online health information (OHI) seeking experiences of adults with chronic health conditions. This is a complicated phenomenon, of which little is known about the precise nature and issues involved. In order to develop a research project that could reflect the complex nature of the area of study and provide both a breadth and depth of knowledge within the field of consumer health informatics, a pragmatic approach to research design was utilised, which ensured that the methodological design was guided by the aims of the research as opposed to any researcher preferences or bias. Ultimately, in order to effectively handle the complex research question, a mixed-methods research approach was adopted to allow for the development of both a breadth and depth of understanding regarding the nature of the studied experiences.

The Mixed-Methods Approach

Mixed-methods research is, by definition, a procedure for collecting, analysing and integrating both qualitative and quantitative data within a single study for the purpose of gaining a more full understanding of a specific research problem (Creswell, 2003, Tashakkori and Teddlie, 2003). The last two decades have seen a vast increase in the number of studies adopting a mixed-methods approach to research design. This rapid proliferation has led to the development of a journal specifically dedicated to the approach (*The Journal of Mixed Methods*) and the amplification of the number of general publications relating to these methodological issues. Notably, included within these publications is *The Handbook of Mixed Methods in Social and Behavioural Research* (Tashakkori and Teddlie, 2003), which has provided both theoretical and practical information to assist researchers in utilising mixed-methodological approaches.

Advocates of this form of research note the rationale for mixing methods to be that neither method used individually would be sufficient to effectively handle the nature of the research problem (Ivankova et al., 2006). Therefore, the grounds for mixing are that, by combining and increasing the number of research strategies used within a single project, it is possible to broaden the dimensions and scope of the research,

allowing for more robust analysis and the development of a more holistic picture of human behaviour (Morse, 2003). Health researchers have been especially interested in combining qualitative and quantitative methods because this approach has great potential for handling the complexity of different factors that influence health (Morse, 1991, Morgan, 1998). Despite the vast potential for mixed-methods research to allow researchers the opportunity to effectively tackle different aspects of complex phenomena within a single study, the assertion that mixed-methods research is a valid form of research within the academic community has been, and continues to be, a significant struggle. Prior to the emergence of mixed methods as a frequently cited methodological approach, the advocates of both qualitative and quantitative research had engaged in an ongoing dispute over the nature of their research paradigms throughout a number of decades. These debates led to the emergence of both qualitative and quantitative purists on opposite sides of the paradigm debate who would not defect from conducting research within the realms of their preferred paradigm. This was often due to the development of significant emotional attachment to one specific approach (Johnson and Onwuegbuzie, 2004). Both sets of methodological purists explicitly advocated their chosen paradigm as superior for conducting research, and rejected the possibility that qualitative and quantitative research paradigms could coexist within a single research study. This belief is the underlying concept behind the incompatibility thesis (Howe, 1988), which suggests that qualitative and quantitative methods are incommensurate. Put simply, the argument adopted by incompatibilists is that the philosophical distinctions are so great between qualitative and quantitative research and their associated paradigms that their respective methods cannot be combined within a single research project. These beliefs are grounded in the fact that qualitative and quantitative methods are each based on very different paradigms, both with a different patterned set of assumptions concerning reality (ontology), opposing views on the knowledge of that reality (epistemology), and separate ways of knowing that reality (methodology) (Guba, 1990). Quantitative research is based on the positivist scientific paradigm, while qualitative research is deeply rooted within the interpretivist/constructivist paradigms. The ontological position of the quantitative paradigm suggests that there is a single truth and an objective reality, whilst the interpretivist/constructivist paradigms assume multiple truths based on an individual's own construction of reality. In addition, epistemologically speaking, quantitative research suggests

researcher and respondent are independent, therefore ensuring objectivity, while qualitative research details that reality does not exist independently of our own minds, therefore positioning the researcher within the research.

The paradigmatic, epistemological and ontological differences between qualitative and quantitative research are extremely pertinent when critiquing the mixed-methodological concept of cross-validation (Campbell and Fiske, 1959). This justification for mixing paradigms within one research project suggests that the aim is to conduct two studies in the hope of coming up with the same conclusion, therefore demonstrating a greater level of validity in the results and the methodology used. A common discussion of cross-validation is provided by Denzin (1970) through his work on the concept of triangulation. Denzin (1970) developed the earlier work of Webb et al. (1966) who suggest a number of means by which a researcher could cross-check their results using different methods in order to ensure increased levels of validity (Webb et al., 1966, Denzin, 1970). Although these concepts have a huge legacy within the development of mixed-method research techniques, they have long been the subject of much criticism, as many academics have suggested that triangulation for the purpose of cross-validation allows the paradigmatic differences between qualitative and quantitative to become blurred, by suggesting that the same phenomenon can be researched in the same way by methodological techniques that relate to a different perspective of the nature of knowledge and reality. The same argument is used by incompatibilists who assume that mixing methods and triangulation go hand in hand. However, the reverse is often true, with triangulation being cited as an extremely rare motivation for conducting mixed-methods research. In fact, an early meta-analysis of mixed-methods studies showed that only three out of the considered 57 studies cited triangulation as motivation for combining methods (Greene et al., 1989). Although it is true that some mixing strategies are adopted uncritically without concern for the underlying paradigms, increasingly mixed-methods researchers are developing techniques that honour paradigmatic differences (Haase and Myers, 1988) when combining qualitative and quantitative research.

A more common justification for combining qualitative and quantitative methods within a single research project is for purposes of complementarity. Studies adopting this rationale aim to combine different methods so that the strengths of one method

can enhance the performance of another (Morgan, 1998). In other words, approaches citing mixing for purposes of complementarity suggest that the researcher intends to mix methods in order to view the same phenomenon from different viewpoints, therefore justifying the use of different approaches. Despite the popularity of this approach in terms of its adoption by the mixed-methods research community, it has also encountered significant criticism in terms of its lack of consideration of paradigmatic differences. Some methodologists suggest that this approach is not advisable if the ultimate goal is to study different aspects of the same phenomenon, because methods from different paradigms are unable to answer research questions in exactly the same way due to the phenomenon under study not being the same across methods (Sale et al., 2002).

In addition to their criticism of traditional notions of complementarity and triangulation, Sale et al. (2002) offer a solution to the qualitative–quantitative debate by suggesting a form of mixed-methods research that acknowledges and respects paradigmatic differences whilst still allowing for the combination of different methods within a single study. They note the importance of accepting that qualitative and quantitative research will inevitably look at different phenomena within the same research area. Their suggestion is to label the phenomenon examined by each method explicitly, thus emphasising the differences that separate qualitative and quantitative research. For example, the OHI-seeking experience could be viewed using qualitative methods in terms of the phenomenon of ‘lived experience’, and in the case of quantitative, the phenomenon could be defined as a ‘measure’. By utilising this approach, it is possible to combine qualitative and quantitative methods within a single research project in order to provide a holistic understanding of complex phenomena, whilst still honouring epistemological and ontological differences between paradigms. This form of mixed-methods research based on reformed notions of complementarity will be adopted within the current research study in order to form a mixed-methods research design that is both practically and philosophically sound.

Research Aims and Objectives

As previously stated, the overall aim of the study was to contribute to the general understanding of the OHI-seeking experiences of adults with chronic health conditions. In order to develop a research project that could provide both a breadth

and depth of information relating to the area of study, a pragmatic approach to research design was utilised to ensure that the study design was guided by the aims of the research as opposed to any researcher preferences or bias. Therefore, the explicit articulation of the study's aims and objectives are of paramount importance.

Aim: Breadth-

To collect broad data relating to the overarching research aim. In order to effectively communicate the aim it was broken down into 5 more specific objectives:

Objectives: Breadth-

- To investigate how people make choices about locating OHI.
- To examine how they decide if it's reliable.
- To explore what they do with OHI after they find it.
- To examine how OHI influences decision-making.
- To investigate how individuals perceive the response from others to their online information- seeking behaviour.

Aim: Depth

One further aim of the study was to achieve a depth of information to complement the broad data. Specifically, this aim was to explore, in a detailed way, how searching for OHI became a meaningful activity for adults who had been diagnosed with chronic health conditions. It was envisaged that the precise nature of experience studied within stage two would be guided by the findings from stage one and so full clarification of this aim could not yet be made. The inclusion of this aim allowed for the development of a richer understanding of the nature of the information-seeking experiences for participants, and the unique and shared meanings that arise from information seeking.

As well as providing a breadth and depth of information relating to the nature of OHI seeking as experienced by adults with chronic health conditions, an additional aim of the study was to review and develop innovative mixed-methods research techniques in order to make an original contribution to the field of research methods.

The final aim of the research was to produce data that could be practically utilised to inform practice and the training of health professionals, and therefore help develop their understanding of the nature of the phenomenon of OHI seeking.

Research Design

A research design was developed pragmatically that would produce a breadth of knowledge relating to the OHI-seeking behaviour of adults with chronic health conditions which could also be used to inform an experiential study that would provide a level of depth to the findings. In order to achieve these aims, a sequential mixed-methods approach was adopted that would include a predominantly quantitative questionnaire followed by phenomenological interviews.

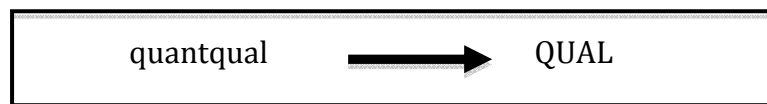


Figure 1. Methodological stages.

Figure 1 shows the nature of the sequential mixed-methods approach that was developed to fulfil the aims of the study. In order to obtain a breadth of information relating to the OHI-seeking experience of adults with chronic health conditions, two predominantly quantitative data collection tools (questionnaires) were developed for the preliminary phase of the research. The questionnaires (Appendices A and B) consisted primarily of quantitative, closed-format questions to allow a large amount of data to be collected from a sizeable sample quickly and relatively easily. In addition, a number of open questions were also included within the questionnaires to ensure that the emerging phenomena were not limited. By including open questions, and allowing for a level of induction to occur using predominantly deductive data collection tools, the questionnaires could also be utilised to identify an appropriate qualitative experiential focus for the second stage of the research project. The aim of the second stage of the research was to provide a sense of depth to the study. This aim was achieved by developing an understanding of the qualitative experiential theme identified within the stage one questionnaire, and to explore in a detailed way how the experience became meaningful for those involved. By including this stage, the research satisfied the study's aim in terms of providing depth to the research findings.

Creswell et al. 2003 suggest that mixed-methods research can be defined as:

The collection or analysis of both quantitative and qualitative data in a single study in which the data are conducted concurrently or sequentially, and are given priority, and involve the integration of the data at one or more stages within the research process. (Creswell et al., 2003, p.212).

The tenets of this definition are echoed by Morgan (1998) who suggests that mixed-methods research designs are accomplished by making two basic decisions: a priority decision that pairs a principal method with the complementary method, and a sequence decision that determines the order of the research. As previously stated, this research was conducted sequentially so that the data from stage one could inform the focus of the second stage of the research, ensuring a level of cohesion throughout the two stages. The place in the process for integration bears a relationship to whether the research is conducted in phases (sequential) or as a single phase (concurrent) (Creswell, 2003). Because this research utilised a sequential procedure, integration within the discussion phase of the study was seen as more appropriate than mixing in the analysis stage. This approach ensures that the stages of the research are kept separate through analysis, facilitating the researchers' ability to respect paradigmatic differences and allowing them to use separate analysis techniques that accurately reflect the nature of the data from each stage. Priority within the current study was given to the qualitative stage in order to emphasise the importance of developing a more detailed view of the meaning of the OHI-seeking experiences for the participants involved. This suggests that higher weighting was given to the qualitative findings within the overall discussion. This decision was made because it reflected my skills as the researcher and emphasised the experiential nature of the overall research question. Morgan (1998) suggests that, taken together, the priority and sequence decisions lead the researcher to adopting one of four basic mixed-method research designs. Figure 2 shows the four possible mixed-method research designs as outlined by Morgan (1998).

<i>Priority Decision</i>			
Principal Method: Quantitative	Principal Method: Qualitative		<i>Sequence Decision</i>
1. Qualitative Preliminary qual→QUANT Purposes: Smaller qualitative study helps guide the data collection in a principally quantitative study. - Can generate hypotheses, develop content for questionnaires and interventions, etc. Example: Focus groups help to develop culturally sensitive versions of a new health promotion campaign.	2. Quantitative Preliminary quant→QUAL Purposes: Smaller quantitative study helps guide the data collection in a principally qualitative study. - Can guide purposive sampling, establish preliminary results to pursue depth, etc. Example: A survey of different units in a hospital locates sites for more extensive ethnographic data collection.	Comp. Method: Preliminary	
3. Qualitative Follow-Up QUANT→qual Purposes: Smaller qualitative study helps evaluate and interpret results from a principally quantitative study. - Can provide interpretations for poorly understood results, help explain outliers, etc. Example: In-depth interviews help to explain why one clinic generates higher levels of patient satisfaction.	4. Quantitative Follow-up QUAL→quant Purposes: Smaller quantitative study helps evaluate and interpret results from a principally qualitative study. - Can generalise results to different samples, test elements of emergent theories, etc. Example: A state-wide survey of a school-based health programme pursues earlier results from a case study.	Comp. Method: Follow-Up	

Figure 2. Complementary combinations of qualitative and quantitative research: The priority sequence model (Morgan, 1998).

The second cell on the above figure (figure 2) shows the suggested design for studies that give priority to a follow-up qualitative stage. Similar to the approach taken within the current study, Morgan (1998) suggests that the knowledge provided by an initial quantitative phase can be used to help guide the decisions the researcher makes in the second stage, and can help focus the analysis of large amounts of qualitative data. Although the current research study is designed in a similar manner to the outline in

cell 2, Morgan's model does not provide an exact template for the current method because this study included a small number of open qualitative questions within the preliminary interview stage.

The approach adopted in the current study and the methodological structure suggested in cell 2 (Morgan, 1998) propose an alternative model for a sequential mixed-methodological design that prioritises the qualitative approach. Traditionally, the researcher would begin with the predominant qualitative stage and continue with the complementary quantitative stage (Creswell, 2003). The theory behind this more conventional approach is that sequencing in this manner allows for theory generation through inductive qualitative research that can then be tested using deductive quantitative measures. This form of sequencing promotes the perception that there is a need to confirm qualitative research, and that it would somehow be inconclusive without the addition of a quantitative stage (Morgan, 1998, Morse, 2003). The current approach was based on an alternative model for sequential mixed-methods that has been adopted and favoured by anthropologists for many years (Pelto and Pelto, 1978). This form of sequencing was adopted because it allowed the knowledge generated from deduction within the quantitative stage to guide the subsequent decisions made for stage two. Therefore, as opposed to using quantitative data to confirm the qualitative findings, the quantitative component was used to help orientate the phenomena researched within stage two to enable focused experiential qualitative research to be conducted. This approach suits the nature of phenomenological research that is focused on a particular experience as opposed to being very general and open-ended in focus.

Ethical Approach

Ethical approval for the study was sought from the Bournemouth University Research Ethics Committee (UREC) in order to comply with the philosophical approach of the study (Appendix C). University ethical approval was needed because the research was conducted within the context of social research and was seen as broader than National Health Service (NHS) research in that it dealt with social issues such as self-management and social support. Therefore, it was considered more appropriate to seek ethical approval through Bournemouth University to ensure consistency between the research and its procedures. By taking a public citizenship approach, and

Methodological Approach

mirroring the aims of health informatics, a philosophical approach was adopted, which empowers individuals with chronic illness as opposed to predefining them in the 'sick role'. Details regarding the specific ethical considerations for each stage of the study are presented within their relevant methods sections.

Chapter 5. Stage One Methods

Introduction

In order to develop a presentation that mirrors the sequential nature of the study, the two methodological stages will be presented separately, beginning with a discussion of the methods that were utilised within stage one.

Research Design

The stage one questionnaire was developed specifically to meet the objectives of the preliminary stage of the research, and therefore make a significant contribution to the study's aims. A unique data collection tool was developed, as there was no 'gold standard' questionnaire available that allowed for the fulfilment of the studies explicit set of objectives. Therefore in order to meet these specific objectives, the questionnaire was developed pragmatically to achieve a level of experimental breadth that was supported by the existing literature.

Previous literature suggests that the first stage of questionnaire development is the identification of the aims and objectives of the data collection tool (Sapsford, 1999, Gillham, 2000, Oppenheim, 2001). As previously noted, stage one consisted of two predominantly quantitative questionnaires that were designed to collect a breadth of information from a relatively large sample of participants regarding the nature of online health information (OHI) seeking experiences (usage questionnaire), and the barriers to OHI seeking (non-usage questionnaire). Specifically, the questionnaires had to fulfil the aims of the study in terms of breadth (see aims and objectives above), produce data that could contribute to the overall discussion of the research area, and help identify interesting phenomena that could focus the second stage of the study. Oppenheim (2001) suggests that, once the aims of a questionnaire have been identified, the literature review should then commence. Within this research project, the two preliminary stages (literature review and objective identification) were conducted concurrently in order to develop objectives that reflected previous literature and research in the area, and produce a relevant and informed data collection tool that could explore existing areas of interest/study. Once the objectives of the study had been identified, they were developed through the process of conceptualisation (Oppenheim, 2001). According to Oppenheim (2001),

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conceptualisation refers to an improved and more detailed statement of the study's objectives being given, preferably with theoretical underpinnings, for example whom should we be asking? And, specifically, what should we ask them about? This process of conceptualisation was realised with a combination of re-reflection on past literature and by engaging in a process of informal feedback. Primarily, this process was conducted by discussions with support group leaders who had experience of working with individuals who were actively seeking health information. This was an extremely useful process and some of the feedback from this stage was included in the final questionnaire design. For example, one support group leader had seen from his personal experiences of working with people with chronic health conditions that the nature of OHI seeking varied depending on the stage of their health condition. He had experienced that people who are newly diagnosed with a chronic health condition tend to desperately seek information to help them self-manage or cure their condition. He described how, later on during the development of the condition (once an individual has learned to live with the chronic health condition and gone through a process of acceptance), they would use OHI in a very different way. This led to the development of 'length of time since diagnosis' as a demographic component of the questionnaire, in order to assess whether this had made an impact on online information seeking.

The concept of a non-usage questionnaire was also uncovered at this stage because it was suggested in an informal discussion with another support group leader that the study would be severely limited by only looking at support group members who used the internet to seek health information. This group leader's justification was that a high proportion of their support group did not have access to these facilities due to functional difficulties and low levels of IT literacy. Additionally, it was considered that perhaps an interesting phenomenon within the overarching research area of OHI-seeking might be those left behind by the digital divide and the barriers that they face (Brodie et al., 2000, Cotten and Gupta, 2004). Therefore, in order to achieve my aim of subject breadth in stage one, a short parallel questionnaire was included for those support group members who had never used the internet to search for health information (Appendix B). This was termed the 'non-usage' questionnaire as opposed to the 'usage' questionnaire (Appendix A). Later on in the questionnaire design process, additional informal feedback from PhD supervisors and peers (people who

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were experienced in both the subject area and questionnaire design) was sought to develop the first drafts of the questionnaires.

In order to assess the study for feasibility, certain decisions needed to be made regarding time limitations, costs and staffing in order to ensure that the overriding aims of the study could be achieved (Oppenheim, 2001). Due to this study being part of a PhD thesis, there were specific considerations that needed to be made to ensure that the design was practical. The nature of the adopted sampling strategy (see below) meant that the purposeful sample for the questionnaire could be accessed within the allocated timeframe and at minimal cost, therefore justifying the study as feasible.

According to the seven stages of survey research design prior to sampling (Oppenheim, 2001), the next stages of questionnaire design involve taking the operationalised aims (hypotheses) and deciding what is going to be investigated and how. Primarily, an initial layout was produced to show the order in which the topics would be approached. Once the key themes had been identified, time was allocated to exploring the development and use of survey tools exploring similar areas within a range of journal articles (Henwood et al., 2003, Murray et al., 2003) and published national surveys (Pew Internet, 2000, Harris Interactive, 2008). This research gave practical examples of how questions could be developed and structured in order to satisfy the objectives of the study.

Gillham (2000) explains that it is essential to think about which topic should come first and how the topics will lead into each other in order to achieve a clustering and progression that will make the questionnaire easier to work through. Initially it was considered that the demographic and internet usage questions may be placed at the beginning of the questionnaire. However, further research into questionnaire development showed that certain demographic questions such as educational achievement would be perceived as 'sensitive questions' and as such should be ordered last on the questionnaire (Leung, 2001). In order for the questions to move from general to more focused topics, the internet usage statistics were placed at the beginning of the survey. Once the reading around the topic of questionnaire design had been completed, and a suitable order had been outlined, the questions for the first version of the questionnaire were drafted. This involved outlining the data that was

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intended to be achieved under each theme and developing a question type that would realise these objectives. Initially, more questions were written than would be needed for the final draft, until a limit of six (maximum) was set for each topic; questions were eliminated based on those deemed as non-essential, or were combined by changes in the wording or structure. The final figure of six was decided on after engaging in a thought storming exercise. It was felt that this number of questions provided a practical balance between including vital information whilst ensuring that the questionnaire remained succinct. Questions were then flagged by their style, for example factual, opinion, perception, open or closed, in order to create a core structure. This was then analysed in more depth to ensure that the question order and type were suitable for achieving the desired outcomes of the study. Options for multiple-choice questions were developed through a process of reviewing the literature and other tools used for measuring similar areas of research.

Oppenheim (2001) states that the final stage of questionnaire design prior to sampling is to conduct a pilot study. Within this stage, the complete questionnaire is tested using the administrative procedures that will be used in the final study (Bourque and Fielder, 2003) to iron out any potential problems. In order to pilot the study effectively, participants were sought with different chronic illnesses, backgrounds, ages, educational levels and general literacy for the pilot study. Primarily, the pilot participants were sought by emailing all Bournemouth University School of Health and Social Care PhD students and asking if they would mind filling in a questionnaire and giving me feedback. This gave me a good level of response for the usage questionnaire (due to recruitment being done by email) and so I also asked for referrals to friends and family who may be eligible to give me feedback on the non-usage questionnaire. As recruitment was sought initially through PhD students, the sample was biased towards people of high educational level and literacy. Therefore, individuals were purposefully selected from outside the university who may have lower education and literacy levels. The final sample size was five for the usage questionnaire and three for the non-usage. As the non-usage questionnaire was much shorter and largely parallel to the usage questionnaire, this sample size was deemed appropriate for a pilot. Participants were requested to give as much detailed feedback as possible on the questionnaire so that the necessary improvements could be made. It was explained that feedback should include signposting ambiguous statements, jargon

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and double-barrelled questions (Oppenheim, 2001). Overall, the feedback was very positive, although a couple of issues did arise. For example, one participant was involved in an independent self-management programme. They suggested that, as well as asking if individuals had been involved with the National Health Service (NHS) Expert Patient Programme, the questionnaire should be designed to uncover if they had been involved in any other self-management programme in order to compare this data. Also, one participant felt that the instructions for ‘Tick one main and as many additional as apply’ instructions needed to be made clearer. It was therefore changed to ‘Tick **one** main and **as many** additional as apply’. The feedback from this process also led to the decision to number the questions for ease of reference.

Various measures were taken throughout the questionnaire design process to ensure the reliability and validity of the survey tool. Reliability refers to the purity and consistency of a measure, its repeatability, or the probability of obtaining the same results again; while validity tells us whether the question, item or score measures what it is meant to measure (Oppenheim, 2001). Levels of reliability set limits on the degree of validity that is possible within a research design; validity cannot rise above a certain point if the measure is inconsistent. Therefore, if a measure has excellent validity it must also be reliable (Fink, 1995, Oppenheim, 2001).

Litwin (1995) explains that there are several types of validity that are typically measured when assessing the performance of a survey instrument: face, content, criterion and construct. Face validity is based on the cursory review of items by untrained judges, and could simply involve showing the tool to a few untrained individuals for feedback (Litwin, 1995). By conducting a pilot study (see above) with untrained individuals, the study was able to assess for face validity. Content validity is a more subjective measure that seeks the views of experts to establish whether or not the items or questions are a well-balanced sample of the content domain to be measured (Oppenheim, 2001). In order to ensure content validity, a process of informal feedback with support group leaders, PhD supervisors and peers was conducted throughout the survey design process. Primarily, the key themes and concepts for implementation were discussed informally with support group leaders to ascertain whether all relevant topics had been included in the survey in order to achieve content validity (Fink, 1995). After the questionnaire had been designed, PhD

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supervisors and peers (people who were experienced in both the subject area and questionnaire design) were asked to read through the questionnaires and give detailed feedback on whether all the possible answers on the multiple-choice questions were available, whether the language was clear and unbiased, whether the order was easy to use, and whether the length was suitable. Not only did this validate the research tool in terms of content, but the process was also used to test the reliability of the questionnaire. This is the case because errors in areas such as language and understanding are a signal that the questionnaire may be unreliable (Fink, 1995). The pilot study and processes of feedback also allowed for feedback of errors in areas such as language and understanding, which could also be a signal that the questionnaire may fail to meet the required reliability levels. In addition to this, specific attention was paid to the order in which the questions were presented on the survey. As previously noted, Gillham (2000) explains that it is essential to think about which topic should come first and how the topics will lead into each other in order to achieve a clustering and progression that will make the questionnaire easier to work through and so ultimately improve reliability (Fink, 1995). This process involved flagging the questions based on style, for example factual, opinion, perception, open and closed, in order to create a core structure that was analysed in more depth to ensure that the question order and type were suitable for achieving the desired outcomes of the study; this therefore additionally improved the validity of the questionnaire.

Link between research questions and questionnaire

Table 4 shows how the questions in the usage questionnaire relate to the key themes outlined as the objectives of stage one of the study.

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Key Theme	Questions
Internet usage/OHI usage	<p>How often do you use the internet? Apart from to seek health information, what do you use the internet for? Approximately how often do you use the internet to seek health information about your condition? Does the amount that you use the internet to seek health information vary? If yes, please indicate which factors make you use the internet to seek health information more/less What are your reasons for seeking health information online? What do you feel is the most important source of health information for you? (Included to use as a demographic comparison with non-usage)</p>
How people make choices about how they find information	<p>To what extent do you agree with the following statement: 'It's easy to find useful and relevant health information on the internet' Do you ever use search engines to find health information online? If yes, which ones have you used? Have you ever been referred to online health information? If so, who was it by? What do you think might help you be more able to locate health information online?</p>
How they decide if it is quality information	<p>To what extent do you agree with the following statement: 'The quality of health information on the internet needs to improve' Do you feel that you are able to accurately assess the quality of online health information? What factors do you consider when assessing website quality? What do you feel would increase your ability to assess the quality of online information?</p>
How they use the information after they find it	<p>What do you do with online health information once you have found it? If you do print it off to show others, who do you show it to?</p>
How participants perceive the response from others to an information-enabled patient	<p>To what extent do you agree with the following statement: 'Bringing online information with me improves my consultations with health professionals' To what extent do you agree with the following statement: 'In my experience, health professionals react positively to me bringing online information into the consultation'</p>
How the information affects you and influences decision-making	<p>Does seeking health information online make you feel more confident to make decisions about your healthcare? Why is this? Does seeking online health information make you more confident about discussing your health and treatment regime with health professionals? (Tick one) Has the information that you have found on the internet assisted in you making decisions about...</p>
Demographics	<p>Please indicate which of the following conditions you have been diagnosed with Please indicate the approximate length of time in years and months since you were diagnosed In general, would you say your health is... Have you ever been involved in an NHS Expert Patient Programme? Have you ever been involved in any other illness self-management programme? If so, please give details: Gender Age Please indicate your highest educational qualification</p>

Table 4. How questions relate to themes in the usage questionnaire.

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The non-usage questionnaire was developed in order to provide a holistic view of the area of study and to avoid limiting the possible outcome phenomena with regards to OHI seeking. Table 5 shows how the questions in the non-usage questionnaire relate to the objectives of the study.

Key Theme	Questions
Internet usage	Have you ever used the internet? How often do you use the internet?
Identifying barriers to internet	Why have you never used the internet?
Identifying barriers to OHI	What do you use the internet for? Why don't you use the internet to access online health information?
Identifying possible resolutions	What would make you more likely to use the internet to access online health information?
Demographics	Please indicate which of the following conditions you have been diagnosed with Please indicate the approximate length of time in years and months since you were diagnosed In general, would you say your health is... Have you ever been involved in an NHS Expert Patient Programme? Have you ever been involved in any other illness self-management programme? If so, please give details: Gender Age Please indicate your highest educational qualification

Table 5. How questions relate to themes in the non-usage questionnaire.

The demographic questions were kept parallel to the usage questionnaire so that comparisons could be made within the final discussion.

The above exercise not only demonstrated a way to review the structure and the specific questions used in the questionnaire, but also acted as an exercise to establish validity by signifying that all the relevant topics relating to the study's aims had been included in the surveys (Fink, 1995).

Ethical Considerations

As quoted in the Bournemouth University research ethics policy and procedures document (Bournemouth University, 2003), the Department of Health asserts that the primary consideration within health and social care is preserving the dignity, rights, safety and wellbeing of participants, and that informed consent is at the heart of ethical research (Department of Health, 2001c). It was considered unnecessary to have written informed consent for the first stage of the study because it would serve to

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identify respondents. Consent was, however, implied by the completion and return of the questionnaires after full explanation of the study, removing the need for written consent (Bournemouth University, 2003). In order to ensure that respondents were aware that completing and returning their questionnaire indicated their consent, this was stated explicitly within the oral briefing process. Furthermore, an outline of how the questionnaire data would be utilised was provided as part of the stage one candidate information sheets (Appendix D). In order to ensure participant anonymity, the names and contact details of participants were not requested, and all data and information relating to the groups that were used to recruit for stage one were stored in locked filing cabinets on the university campus or at home so as to avoid inadvertent disclosure (British Psychological Society, 2006).

In order to prevent the risk of psychological harm, respondents were fully informed about the study prior to taking part through oral briefing, and were also provided with a candidate information sheet (Appendix D) explaining the nature of the study. The information sheet also contained my contact details (in case they had any further questions), information about how the data would be used, contact details of the research supervisors (in case they had complaints), and an account of their right to withdraw from the study at any time without explanation. It also explained to participants that their involvement was completely voluntary, and that if they wished to receive further information relating to the study once it had been completed, they could apply to receive a summary document.

Minor physical risks to the researcher whilst conducting the research were identified, predominantly relating to travelling to and from support group meetings. However, on reflection, these were regarded as no more of a risk than would be taken in general life and were branded as a trivial risks; no further action was therefore required.

Sampling

The stage one sampling procedure utilised a purposeful technique that involved selecting information-rich cases for in-depth study. Patton (1990) describes a number of different ways to conduct purposeful sampling, depending on the objectives of the study. The technique adopted by stage one of the current study was criterion sampling (Patton, 1990), where a specific set of criteria are set and participants are then

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selected in line with this description. The criteria for participants within stage one were as follows:

- Aged 18+ years
- Diagnosed with at least one chronic health condition
- Capable of giving their own consent

Participants who were over 18 years old and were capable of providing their own consent were recruited in line with the ethical approval sought through Bournemouth University. Participants for stage one of the study were recruited through support groups because a public citizenship model was adopted (see ethics). The adoption of this recruitment procedure meant that stage one participants were actively seeking support for their condition and may therefore have been a richer source of information-seeking information than the general public. It was foreseen as vital to appreciate what may differentiate this sample from other people living with a chronic illness (for example, support group members have publicly acknowledged that they are living with a chronic condition (Rosenberg, 1984)). Individuals who are not comfortable about openly declaring that they are living with a chronic illness may use the anonymous space of the internet in a different way. Recruiting through support groups also allowed me to gain access to a larger pool of potential respondents than if participants were recruited singularly or through referral. This was beneficial because I was able to achieve a relatively sizeable sample for stage one of the study.

A number of different support groups dealing with many different chronic health conditions were approached in order to provide data from a range of groups, including groups for people who had suffered strokes, haematological cancers, diabetes, myalgic encephalomyelitis (ME), multiple sclerosis (MS), brain injuries, general cancer, muscular dystrophy, eating disorders and osteoporosis. All groups were located on the south coast of England throughout the counties of Dorset and Hampshire, which helped to maximise data collection potential within the timeframe and reduce the possibility of socio-cultural and geographic variations. Although it would be an interesting research project to look at the differences between this specific sample and others, for example non-support group members or people in the north of England, these were not the aims of this study. Therefore, it is sufficient to

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appreciate the possible differences between this sample and others as opposed to conducting research into how they are different. The details of these groups were found online through Dorset and Hampshire council websites and support group directories. They were located in this way so as not to exclude groups that do not have their own website and possibly have less of a chance of having members who are active online. The support group leaders for the groups were contacted primarily by letter (Appendix E) which introduced myself as the researcher, described the research that I was hoping to conduct and asked if I could visit the group in question to present the details of the study and attempt to recruit participants for the stage one questionnaires. This letter was followed by a phone call a week later in order to maximise the response and provide an opportunity for the support group leaders to ask any questions that they had relating to the initial letter.

From this contact, appointments were arranged to attend nine support group meetings to recruit for participants. These included two diabetes support groups, two stroke groups, one MS group, one ME group, one haematological cancer support group, one group for adults with brain injuries and one group for people diagnosed with osteoporosis. There were issues with gaining access to the eating disorders support group due to the support group leaders perceiving a need to keep the identities of support group members private. Furthermore, the muscular dystrophy and general cancer groups were in the process of disbanding so I was unable to visit any of these support groups to recruit participants. When I performed the group visits, it became clear that none of the members of the support group for adults with brain injuries would be able to complete the questionnaire and provide their own informed consent. Therefore, with the agreement of the support group leader, this group was not used as part of the stage one recruitment.

During the meetings with the eight remaining support groups, the details of the study and the questionnaires were described to support group members. If participants were happy to proceed with their involvement in stage one of the study, they were provided with a stage one candidate information sheet (Appendix D) and the questionnaire that was relevant to their OHI-seeking experience (Appendices A or B). In order to ensure that participants were aware that completion and return of the questionnaire automatically provided consent for their data to be used within the research, this was

explained fully as a part of the oral briefing process. Participants were then asked to read the information sheet in order to inform them about the study, how the data would be used and the complaints procedure. Then, if they were still happy to be involved, they were asked to complete their questionnaire and return it to me using the freepost return envelope provided.

Sample size

When calculating an appropriate sample size for research projects, a number of factors need to be considered, such as how the data will be utilised and for what purpose. Because it was not intended for the stage one data to be used to make inferences based on the wider population, it was considered inappropriate to make sample size calculations in order to achieve true experimental validity. Therefore, to obtain a breadth of questionnaire data from as many people as possible, data was obtained from the maximum number of participants within the available timeframe. Thomas (2000) states that a reasonable sample size for a thesis study would exceed 100 participants within the social sciences. Therefore, the aim of this study was to gain a reasonable sample size of 120 responses with a minimum requirement of 100. Certain measures were put in place to ensure the maximum response rate was realised, including a full explanation of selection for the study, the promise of confidentiality and anonymity, building rapport with participants, and reviewing the length and appearance of the questionnaire. All these factors, when approached correctly, have been shown to increase the response rate (Oppenheim, 2001). The progress of the response rate will be discussed in greater detail within the stage one results section.

Data Analysis

The following section will discuss how the quantitative data obtained using the stage one questionnaire was statistically analysed.

Stage One: Quantitative Analysis

Initially, descriptive statistics were utilised to analyse the quantitative components of stage one of the study. This form of analysis allowed for quantitative summarisation of the data and helped develop a picture of 'if' and 'how' the participants operated as information-enabled patients by seeking information relating to their health online.

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This approach complemented the philosophical underpinnings of both the study and the adopted methodology, and had the potential to present the breadth of results in a manner that allowed for the identification of any interesting phenomena that arose from within the sample. Additional depth was provided to the analysis by the utilisation of a number of non-parametric statistical techniques, which demonstrated potential relationships within and between variables. Because a large proportion of the quantitative data that was collected was nominal or ordinal, non-parametric statistics were the most appropriate tools for studying relationships between variables. This was because the scale of measurement is not of equal interval or ratio scaling, therefore rendering parametric statistics unsuitable. Although a small amount of interval data was also collected, it was decided that non-parametric statistics would also be a more appropriate form of analysis for this data due to the sample size. The following non-parametric statistical tests were used to analyse stage one data:

Spearman's rho (rank correlation) (r):

Spearman's rho is a non-parametric test used to measure the association or correlation between variables that include ordinal data, and is used when the Pearson correlation is shown to be unsuitable as a measure of the strength of association between measured variables (Ariola, 2006). The correlation or measure of association describes the degree of relationship between two variables. An example of where it would be appropriate to use Spearman's rho within this study would be when measuring the degree of relationship between participant age (ratio) and education (ordinal).

Phi coefficient (ϕ):

The phi coefficient is a measure of association for two binary variables (Peers, 1997). An example of when it would be appropriate to use this statistical test within the following analyses would be to measure associations between gender (male or female) and group (usage or non-usage).

Mann-Whitney (U):

The Mann-Whitney test is the non-parametric alternative to the independent samples t test and is used to compare the means of two independent groups (Morgan, 2004). It is a test of homogeneity and is used to verify the significance of agreement of two

distributions. An example of where it would be appropriate to use the Mann-Whitney test would be when comparing demographic data from the internet usage and non-usage groups, such as age.

The following section will outline how the qualitative data from the stage one questionnaire was analysed.

Stage One: Qualitative Analysis

Thematic analysis was employed in order to analyse the qualitative data obtained from open-ended questions during stage one of the study. Thematic analysis involves the search for and identification of common themes that run throughout sources of qualitative data (Morse & Field, 1995). Specifically thematic analysis provides a qualitative approach to data analysis that allows for higher levels of induction than other qualitative techniques such as content analysis (Ezzy, 2002). As previously stated, the objective of including qualitative open-ended questions within the stage one questionnaire was to allow a level of induction to occur in a predominantly quantitative and deductive data collection tool. Therefore thematic analysis was adopted in order to fulfil the requirement of induction, and therefore facilitate the emergence of the relevant phenomena to help inform stage two of the research. Furthermore, Boyatzis (1998) confirms that a thematic approach to qualitative data analysis is recommended when conducting preliminary studies and it “helps the researcher focus, formulate hypotheses, or build a mode of probably causality” (p. 129). Boyatzis (1998) specifically describes four stages to thematic data analysis

1. Sensing Themes
2. Doing It Reliably
3. Developing Codes
4. Interpreting

Within the current study, the stage of sensing themes was conducted by examining the qualitative excerpts line by line in order to get a sense of potential themes that related to the OHI seeking experience. This allowed for the preliminary development of key themes within the data. The second stage was conducted by ensuring that the analysis was approached without prior pre-conceptions about the data, and by revisiting the

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data at different times in order to reduce the influence of ‘mood and state’ (Boyatzis,1998). Boyatzis (1998) explains that returning to the data over a period of time minimises the risk of the researcher’s mood and state affecting the reliability of the data. The next stage involved formally coding the data so that it could be managed into common and unique themes. This involved labelling the themes with a relevant title e.g. ‘Age Barrier (AB)’, and identifying the presence of the themes within the data. The final stage of the analysis involved the interpretation and discussion of the themes that emerged from the analysis in order to provide inductive data that could facilitate the identification of key issues and concepts within the responses to open questions.

As previously mentioned, the thematically analysed qualitative findings will be discussed alongside the stage one statistical data in order to provide a depth of understanding about the nature of OHI seeking.

Stage Two Development

As previously stated, one of the objectives of the stage one questionnaire was to identify an appropriate and relevant phenomenological focus for stage two of the study. It was planned prior to stage one data collection that stage two would adopt a phenomenological approach in order to satisfy the depth aims of the study. This was done by exploring in a detailed way how searching for OHI became a meaningful activity for adults who had been diagnosed with chronic health conditions. By utilising a phenomenological approach, it would be possible to collect focused experiential data relating to the predetermined foci that would be outlined by stage one. To reflect the sequential nature of the research project, a discussion of phenomenological qualitative research and the development of stage two utilising stage one data, including the sampling and implementation strategy for stage two, will be presented after the stage one results section prior to the presentation of stage two results.

Chapter 6. Stage One Results

Introduction

The stage one questionnaires (Appendices A and B) were designed to be predominantly quantitative tools, utilising closed questions to provide a breadth of knowledge about the online health information (OHI)-seeking experiences of individuals living with chronic illness, and to allow high volumes of information to be collected from a large sample quickly and efficiently. To provide an additional level of depth to the analysis, a small number of qualitative open-ended questions were also included within the questionnaires in order to produce a research tool that complements the complex nature of the phenomenon and doesn't limit the emerging themes from within the data. Although the qualitative and quantitative elements of stage one have been analysed separately in order to respect epistemological differences between the data types, these analyses will be presented side by side within this chapter in order to provide an overall picture of the nature of the phenomenon of OHI seeking. Prior to the presentation of the analyses, the following section will discuss in detail the participant response rates within stage one.

Response Rate

Period	Questionnaires Distributed	Questionnaires Returned	Response Rate
Part 1 June 2008–October 2008	197	63	31.98%
Part 2 October 2008–January 2009	72	37	51.39%
Part 1+2 June 2008–January 2009	269	100	37.18%

Table 6. Response rates.

The response rate was calculated during stage one data collection in order to assess whether the predetermined minimum sample size could be recruited within the timescale for the study. During part one of stage one data collection (June–October 2008), 197 questionnaires were distributed but only 63 were returned, providing a response rate of 31.98% (n=63). It was felt that this response rate was not sufficient to

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recruit the desired number of participants (minimum of 100) within the timescale, and that changes would need to be made to the recruitment procedure to yield a greater return. In order to design suitable interventions to help improve the response rate, feedback was taken from the support group leaders involved with the study to help ascertain possible reasons why the response rate was relatively low. The feedback suggested that the support group leaders were aware that a number of participants had functional problems that prevented them from completing the questionnaire and posting it back without assistance. Therefore, it was decided that it would be appropriate to offer participants the options of either taking the questionnaire away to complete at their own pace and within their home environment, or to complete the questionnaire at the support group meeting with my assistance. The assistance involved reading out all the questionnaire information and questions, listening to their responses and completing the questionnaire on their behalf using their own wording. One important consideration that was made before adopting this approach was ensuring that the participant was not influenced into giving a particular response. After offering the option of additional assistance to participants, the response rate improved markedly. A further 72 questionnaires were distributed and 37 were returned completed. Therefore, the response rate for the second part of stage one recruitment was 51.39% (n=37). Because the response rate for the first part of recruitment was only 31.98% (n=63), offering participants additional assistance therefore improved the response rate by 62%. The overall response rate for the whole study was 37.18% (n=100).

The following section will provide an explanation of how the data from the stage one questionnaire will be presented within this chapter.

Presentation

The results from stage one of the study have been organised into eight distinct sections for presentation. The first of these will offer a demographic description of the participants' characteristics; the second will offer a comparison between the two participant groups (usage and non-usage); the third will outline the barriers to usage (as provided by the non-usage questionnaire). The subsequent five sections will be based upon the five objectives of stage one of the study in terms of providing a

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description of OHI seeking for individuals that have been diagnosed with a chronic health condition.

The following section will provide a descriptive statistical summary of the demographic data that was collected from stage one.

Analysis of Demographic Data

Basic demographic data was collected from all participants to allow for effective quantitative summarisation and to provide an accurate description of the sample. Results demonstrated that 63% (n=63) of the participants were female and 37% (n=37) were male, and that the mean age of participants was 63.41 years (range=30–89 years, SD=2.58, mode=75, median=64). Figure 3 below shows that 54% (n=54) of the participants had no formal educational qualifications, while 15% (n=15) cited GCSE or equivalent as their highest educational qualification, 1% (n=1) A-level or equivalent, 5% (n=5) GNVQ or equivalent, 8% (n=8) HND/Diploma, 11% (n=11) to degree level, 4% (n=4) Master's and 2% (n=2) PhD.

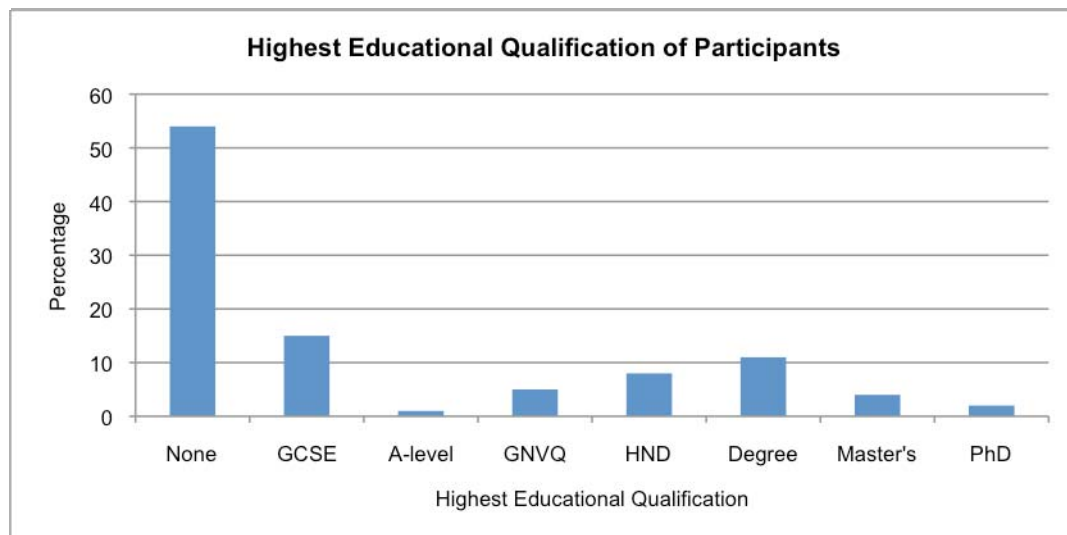


Figure 3. Highest educational qualification of participants.

The participants had been diagnosed with a variety of chronic conditions and frequently had been diagnosed with multiple conditions. Figure 4 shows the frequency of participants diagnosed with each chronic condition. Other chronic illnesses included ME, anxiety, depression, Parkinson's and epilepsy.

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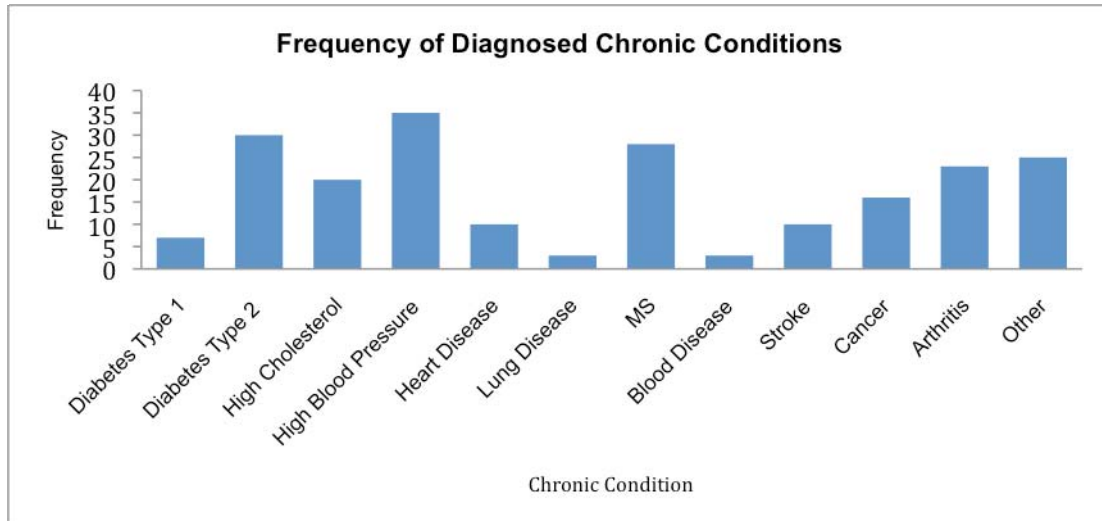


Figure 4. Frequency of diagnosed chronic conditions.

The length of time since diagnosis also varied greatly within the sample (mean=11.88, range=1–45 years, SD=9.56, median=8, mode=multiple).

Perceived health status was calculated by asking participants to answer the question ‘In general, would you say your health is...’. Figure 5 shows the percentage of participants that gave each result.

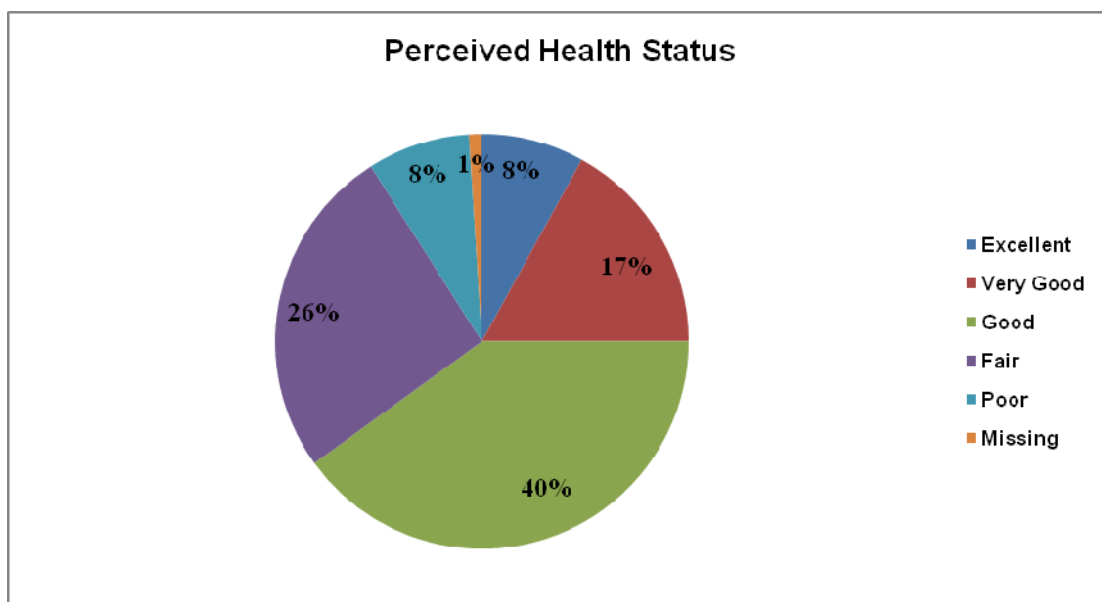


Figure 5. Participants perceived health status.

Data was also collected to identify whether participants had been involved in self-management programmes, to ascertain whether this had achieved an effect on their OHI-seeking experiences. Findings showed that 10% (n=10) of participants had been

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involved with the National Health Service (NHS) Expert Patient Programme whilst 12% (n=12) had been involved in another self-management programme.

Summary

The mean age of respondents was 63 years, although the youngest was only 30 years old and the oldest was 89 years old. Over half of the participants had no formal educational qualification at all. Although a number of participants noted suffering from multiple chronic health conditions, and their most recently diagnosed condition was on average 11 years ago, the majority of participants perceived themselves to be in good health, with only 34% (n=34) stating that their health was considered fair or poor.

Group Comparisons

Participants were placed into one of two distinct categories: those who had used OHI in the past and those who had never used OHI. Both groups were asked to complete different questionnaires. The process of participant briefing that took place prior to stage one data collection revealed that 45% (n=45) of participants had previously used OHI, thus making them eligible to complete the usage questionnaire. The remaining 55% (n=55) of participants who had never used the internet to locate OHI were asked to complete the non-usage questionnaire. The results from these parallel questions for usage and non-usage participants appear below.

Internet usage

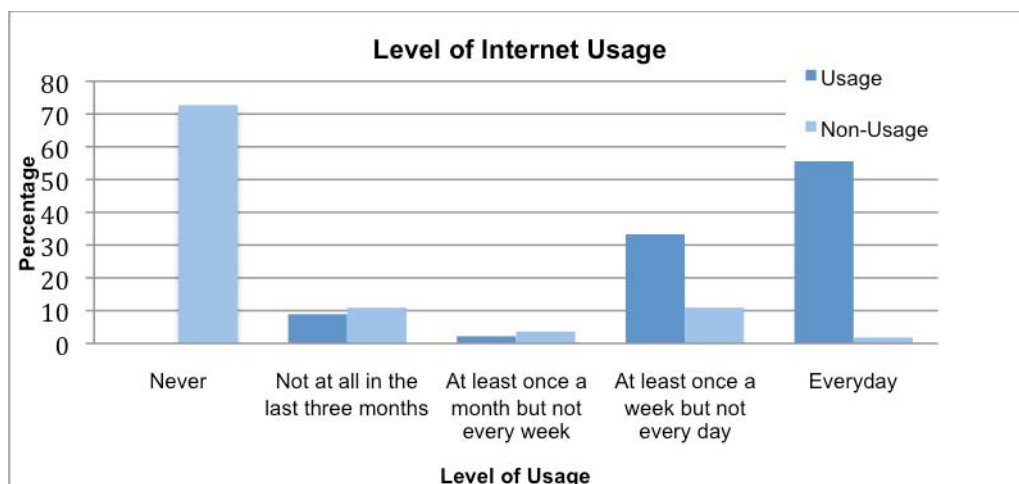


Figure 6. Participants level of internet usage.

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Participants completing the usage questionnaire for OHI were more likely to use the internet more frequently than those completing the non-usage questionnaire. Figure 6 shows that whilst 55.6% (n=25) of usage participants claimed to use the internet every day, only 1.8% (n=1) of non-usage participants recorded the same level of usage. In addition to these figures, 72.7% (n=40) of non-usage participants stated that they had never used the internet at all. A Mann-Whitney test was used to see if there was a significant difference in the mean internet usage for the two groups. Results showed that the usage group had a significantly higher mean for internet usage than the non-usage group ($U(98) 128.50, p < 0.01$).

Internet activities

Excluding OHI seeking, general internet activities undertaken proved to be very similar between the two groups, with email as the most popular online activity for both samples (See Figure 7 below).

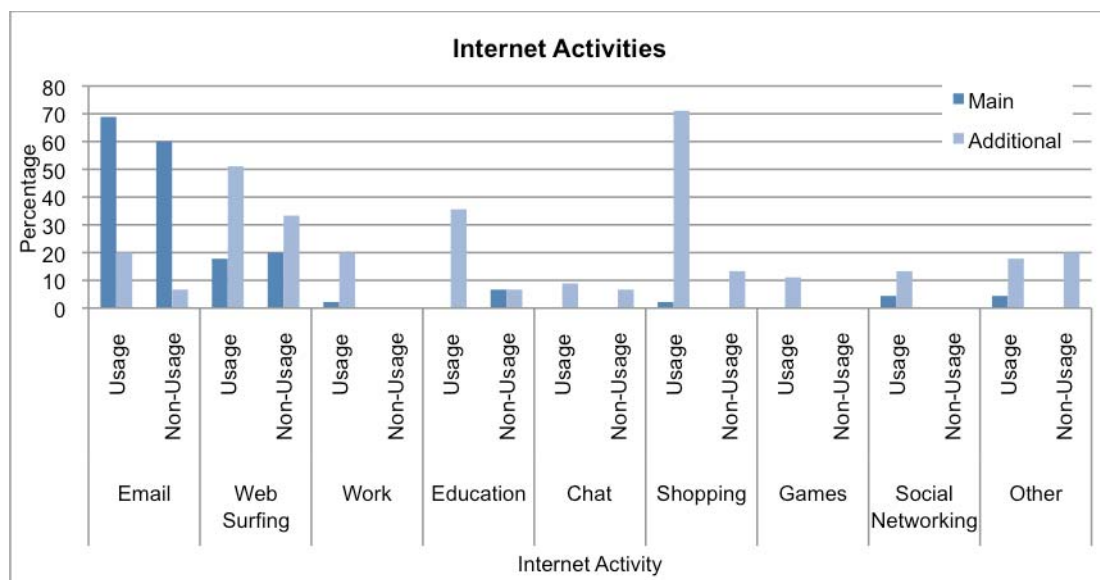


Figure 7. Participants Internet activities.

Health information sources

Health professionals were cited as the main source of health information for both groups (usage: 64.4%, n=29; non-usage: 61.8%, n=34). For the usage group, the internet was the second most popular choice as the main information source, with 22.2% (n=10) of the participants stating it as their primary source of health information. Other sources of OHI for participants included patient information leaflets, books, pharmacists and the media.

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Gender

Although there was a higher proportion of females in the non-usage group (females: 69.1%, n=38; males: 30.9%, n=17) than in the usage group (females: 55.6%, n=25; males: 44.4%, n=20), a test to determine the phi coefficient showed no significant measure of association between group and gender ($\phi(98) = .139, p > 0.05$).

Age

Figure 8 shows that the mean age of the non-usage group (69.13 years, range=44–89, SD=9.416, median=70 years, mode=75 years) was 22.5% higher than the usage group (56.42 years, range=30-84, SD=12.51, median=59 years, mode=multiple). Results of a Mann-Whitney test showed a highly significant difference between the means of the two groups ($U(98) = 18.5, p < 0.01$).

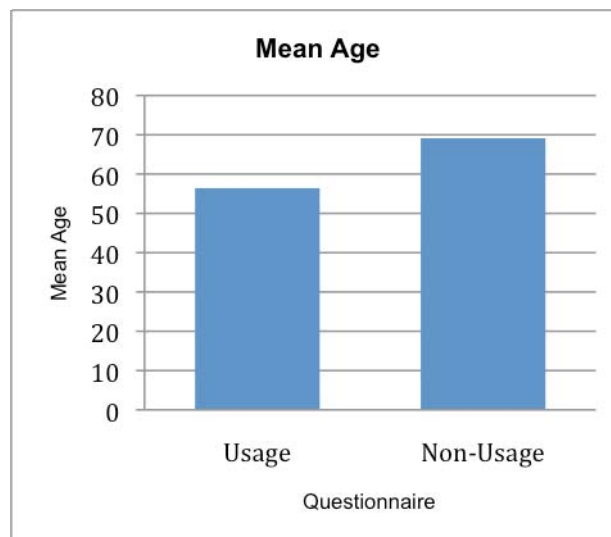


Figure 8- Mean age of usage and non-usage groups.

Education

Comparisons were also made between the highest educational qualifications of participants within the two groups. An independent samples test using Mann-Whitney showed that non-usage participants were significantly more likely to have no formal educational qualifications than participants who had sought OHI in the past ($U(100) = 634.5, p < 0.01$). Results also demonstrated a higher number of usage than non-usage participants in all educational categories. An additional Mann-Whitney test showed

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that the non-usage group had a statistically lower mean highest educational status rank compared with the usage group ($U(98) 634.5, p<0.01$).

Although the mean age and education levels for the two groups were significantly different, the two variables were also strongly correlated with each other ($r(98)=.456, p<0.01$), suggesting a partial effect from an external variable.

Length of time since diagnosis

The mean length of time since diagnosis for the usage group was 11.39 years (range=1–33, $SD=9.54$, median=8, mode=8) and for the non-usage group it was 12.25 years (range=1–45, $SD=9636$, median=10, mode=multiple). A Mann-Whitney test to compare the means of these two groups showed that there was no significant difference in the length of time since diagnosis between the usage and non-usage groups ($U(95) 1061, p>0.05$).

Perceived health status

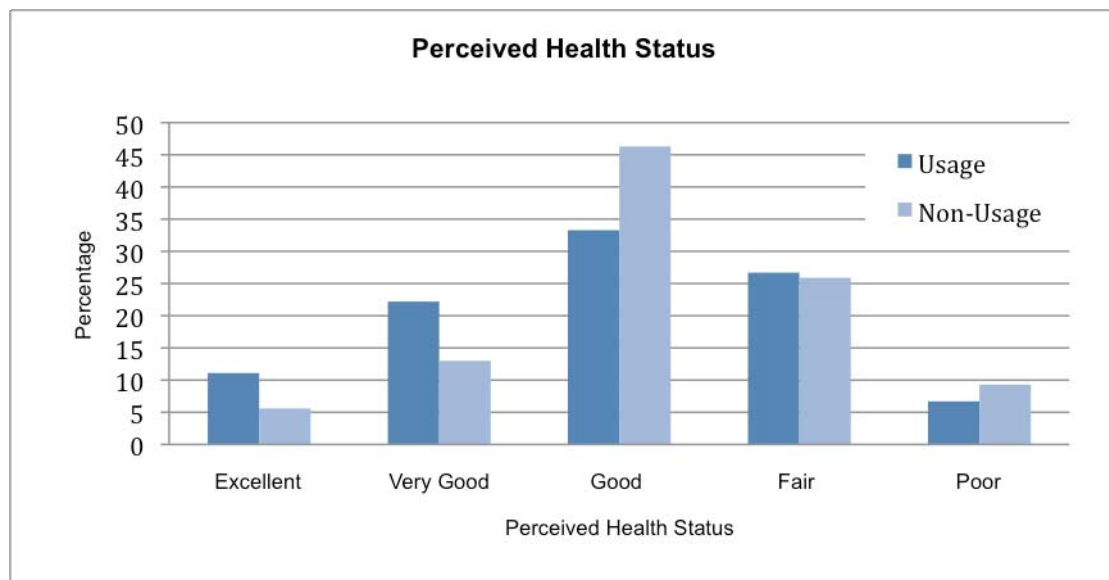


Figure 9. Perceived health status of usage and non-usage participants.

Figure 9 shows the number of participants who chose each rank for perceived health status for the usage and non-usage groups. Despite visible differences, a Mann-Whitney test demonstrated no significant differences in the means of the two groups in terms of health status ($U(97) 1068.5, p>0.05$).

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Self-management programmes

Participants from both groups were asked to state if they had ever been involved with the NHS Expert Patient Programme, or any other chronic illness self-management programme. Of the responses, 11.1% (n=5) of usage participants and 9.1% (n=5) of non-usage participants had been involved in the NHS Expert Patient Programme, while 20% (n=9) of usage and 5.5% (n=3) of non-usage stated being previously involved with other self-management programmes. Overall, 26.6% (n=12) of usage participants had been involved in a programme as opposed to 14.6% (n=8) of non-usage participants. Tests for a measure of association between binary variable (groups and involvement in self-management programmes) showed that there was no association between whether people used OHI and whether they had been involved in the Expert Patient Programme ($\phi(96) 0.035, p>0.05$), and only a very slight correlation between involvement in other self-management programmes and whether they had used OHI ($\phi(97) 0.220, p<0.05$). There was also no correlation between involvement in a self-management programme or not and use of OHI ($\phi(96) .154, p>0.05$).

Summary

A minority of 45% (n=45) of participants had used OHI in the past. Those who had used OHI tended to be younger and had higher educational qualifications. There was no correlation between involvement in a self-management programme and OHI use.

Reasons for Non-usage

This section will discuss the reasons non-usage participants gave for not having ever used OHI.

Although the stage one quantitative data shows that older age, lower levels of formal education and low levels of internet usage were all barriers to OHI seeking, the inclusion of qualitative open-ended questions within stage one provided additional depth to the discussion of why some people were not using the internet in this way by asking non-users to provide details about why they had not used OHI.

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Reasons for not using the internet

Qualitative data from the questionnaire showed that the reasons participants gave for not using the internet generally varied greatly. The most common theme throughout the responses was a lack of equipment or internet connection. Some participants also linked this with the expense involved in using the internet. In addition, participants explained that a lack of understanding/knowledge regarding computer use acted as a barrier to them using the internet. Others felt that there was no need for them to use the internet, with some participants claiming that this was due to them being satisfied with other sources of health information. One participant noted that using the internet may be a future possibility for them:

“Never had the need till recently – now everything seems to be on the net.”

The three other barriers frequently referred to by participants were age issues, functional issues and trust issues. The respondents who cited age issues made a connection between increased age and ability to use the internet by claiming that they were “too old”. A number of respondents mentioned functional issues as a barrier to using the internet, noting that it can be “frustrating”. The functional issues discussed ranged from physical ailments, such as pain in the hands, to issues with patience and concentration. A couple of participants also referred to trust issues, with one specifically noting:

“We have got a computer, my husband uses it, but I’m a bit wary.”

Reasons for not using the internet to look for OHI

Although there were fewer responses to the question ‘Why don’t you use the internet to access OHI?’, the themes identified within the answers were very similar to those revealed within the previous responses. Participants again noted lack of equipment or internet connection as a barrier to OHI, along with lack of knowledge/understanding and trust, and functional issues. However, age issues and expense were not mentioned within these responses. Some participants also deemed OHI unnecessary, as in the previous question, with one participant claiming that it “feels like I have enough info”. Some participants noted that they had not considered the use of OHI, and a few admitted to being unaware that OHI even existed:

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“Unaware online health information available.”

“Never heard of it before.”

What would make participants more likely to seek OHI?

Participants were specifically asked ‘What would make you more likely to use the internet to access OHI?’. There were a few suggestions of personal and general interventions that the participants felt may improve the chances of them using OHI. Personal interventions included an increase in their own knowledge regarding OHI seeking and the resolution of functional issues. General interventions were also suggested by participants and included the following:

“Star system to show that information has been validated by reputable medical professionals.”

“A list of ‘Approved’ websites.”

One participant noted that if they were “diagnosed w/ something else”, they would be more likely to use OHI, while another explained that:

“After answered 5) above I will now have a go at this.”

Summary

The most common reason for not using the internet was a lack of equipment or internet connection. Some participants linked this to expense. Other reasons included a lack of knowledge/understanding regarding computer use, feeling that there was no need for them to use the internet, age issues, trust issues and functional issues. The reasons for not using OHI were similar to the reasons for not using the internet generally. Participants again noted lack of equipment or internet connection as a barrier to OHI, along with lack of knowledge/understanding and trust, and functional issues. Some respondents explained that they were unaware that OHI even existed. Participants stated that increased knowledge and a reduction in functional issues, as

well as improvements to the OHI-seeking experience, would make them more likely to search for OHI.

Stage One Objectives

In addition to the aforementioned parallel questions asked to both usage and non-usage participants, the usage questionnaire also contained a number of unique questions designed to help describe in greater detail the nature of OHI seeking for those involved. These questions were included to satisfy the five aims outlined for the first stage of the study. The following analysis sections will outline each of the stage one aims in turn alongside the data that was collected using the usage questionnaire, to help satisfy each aim and understand the nature of OHI seeking in more depth.

Objective 1: Find out how people make choices about how they locate online health information

The first objective of stage one was to seek to understand how participants made choices about locating OHI, in order to achieve a breadth of knowledge about the OHI-seeking experiences of people with a chronic illness. A number of questions were designed to facilitate the discovery of this information.

Ease of locating online health information

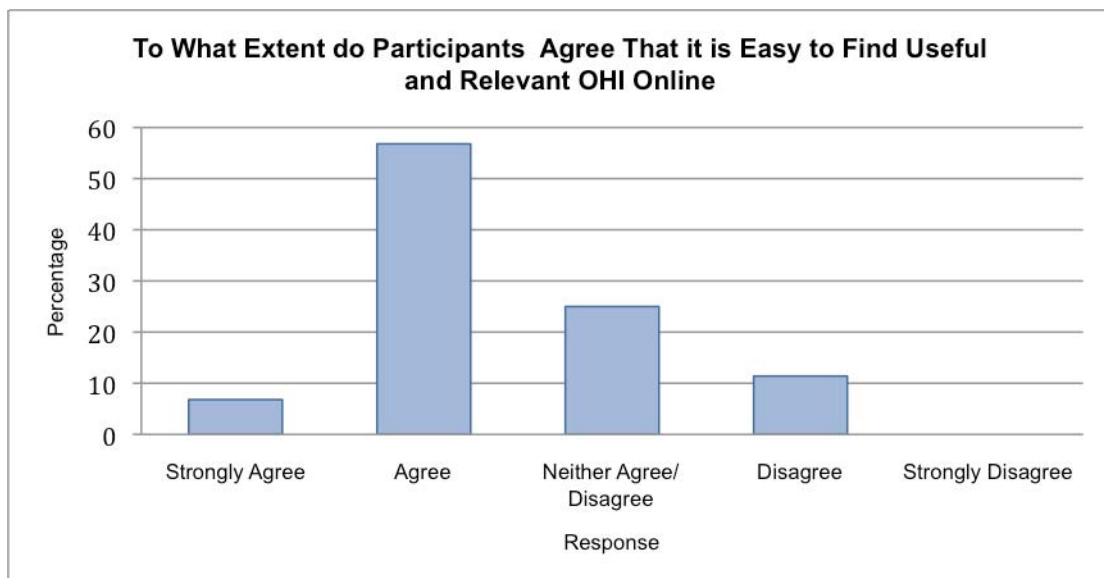


Figure 10. The extent to which participants agree that it is easy to find useful and relevant OHI.

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Figure 10 shows that the majority of participants either agreed or strongly agreed that it was easy to find useful and relevant OHI online. A number of non-parametric correlations (Spearman's rho) showed that there were no significant correlations between internet usage levels and whether individuals felt able to easily locate useful and relevant health information on the internet ($r(42) = -.280, p > 0.05$), ease of locating and age ($r(42) = -.222, p > 0.05$), education ($r(42) = .006, p > 0.05$), health status ($r(42) = .008, p > 0.05$) or length of time since diagnosis ($r(39) = -.045, p > 0.05$). Tests for homogeneity (Mann-Whitney) were also run to compare the ease of location for different populations. There were no significant differences in the mean score for ease of location for those who had and those who had not been referred to OHI ($U(42) = 183, p > 0.05$), those who had used search engines and those who had not ($U(42) = 126, p > 0.05$) or between males and females ($U(42) = 126, p > 0.05$). However, an additional Mann-Whitney test showed that individuals who felt less able to assess OHI quality were more likely to struggle in finding useful and relevant OHI online ($U(43) = 133.5, p < 0.05$).

The range of additional comments provided alongside responses to this question described the barriers that participants perceived needed to be overcome in order to find useful and relevant health information on the internet. A number of participants described the need to “wade through” vast amounts of information, and mentioned being faced with sites with “vested interests” such as those “advertising” and “selling remedies”. Others noted that information was often misleading, contradictory or not recently updated, with one participant specifically noting that information could be “as much as 2–3 years old”. Accuracy, reliability and quality of information were all displayed as concerns for many participants. One participant specifically stated that they felt that the process of locating OHI was time consuming, while another expressed that:

“It’s easy if you know what information to input and how to select appropriate websites.”

Search engines and referral

A majority of 77.8% ($n=35$) of participants used search engines to locate OHI. Mean internet usage was significantly higher for participants who used search engines

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(U(43) 73, $p < 0.01$), as was OHI usage (U(43) 81.5, $p < 0.01$). A phi coefficient showed no relationship between search engine usage and referral to OHI ($\phi(43) .265$, $p > 0.05$), or search engine usage and gender ($\phi(43) -0.48$, $p > 0.05$). Further to this, two Mann-Whitney tests were conducted and also found no significant difference in the mean ages and highest education qualification for those who had and those who had not used search engines (age: U(43) 110.5, $p > 0.05$; education: U(43) 146, $p > 0.05$). The search engines that participants stated using were Google, Yahoo, Ask, AltaVista and Internet Explorer. Some participants also mentioned the Department of Health search and library tools as well as specialist searches such as Grateful Med, Ingenta and Jstor. Only 33.3% ($n=15$) of participants had ever been referred to OHI.

Possible interventions

When asked the open question ‘What do you think might help you be more able to locate health information online?’, respondents noted a number of specific qualities that they perceived as needing to improve. These included transparency of sources and authorship, nationality of information (UK preferred), improved links and navigation and a general increase in information quality. One participant also noted that they felt access to academic information through an access management system (Athens) currently helped them locate OHI more effectively. A number of responses also affirmed that participants believed that being provided with general advice, or as stated more frequently, advice from healthcare professionals, would assist them in being able to locate useful and relevant OHI. Other recommendations of interventions included providing “some kind of mark” that would distinguish the good quality information from the poor, and the creation of a universal portal for OHI:

“Trustworthy resource that holds the information.”

“Maybe a standard website to just type in one comment and pick up all info.”

Some participants also identified existing barriers to locating relevant and useful OHI, such as knowledge/understanding and trust, and functional issues, while others suggested from their responses that they felt that locating OHI was not an issue for them.

Stage One Results

Summary

Results showed that the majority of OHI users agreed or strongly agreed that it was easy to find useful and relevant health information online. Those who agreed with this statement were more likely to rate their ability to assess OHI as higher than those who disagreed. Those who disagreed with the statement made additional note within their comments of the high volume of OHI and the dubious quality. Participants demonstrated different means of locating OHI, such as using search engines (77.8%, n=35) and referral (33.3%, n=15). Participants also suggested a number of interventions that may help people locate OHI.

Objective 2: Find out how people decide if OHI is quality information

The second objective of the stage one questionnaire involved ascertaining what the participants' opinions were of OHI quality, identifying their perceived ability to assess OHI quality and uncovering the methods that they used to make these quality judgements.

Participants' opinions of OHI quality

In order to establish the perceived extent of the OHI quality issue, participants were primarily asked to what extent they agreed with the statement 'The quality of health information on the internet needs to improve'.

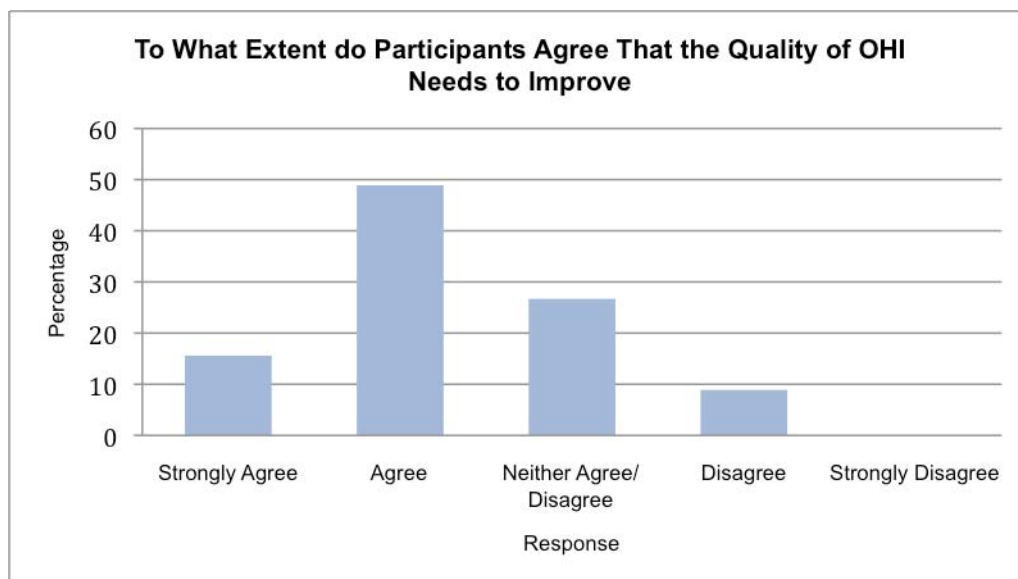


Figure 11. The extent to which participants agree that the quality of OHI needs to improve.

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Figure 11 shows that a majority of 64.5% (n=29) of participants either agreed (48.9%, n=22) or strongly agreed (15.6%, n=7) that OHI quality needs to improve; 26.7% (n=12) of the participants neither agreed nor disagreed and only 8.9% (n=4) disagreed with the statement. A number of non-parametric correlations (Spearman's rho) were run in order to measure the association between variables. Results showed a weak negative correlation between the responses to this question and educational level ($r(43) = -.353, p < 0.05$). This means less educated participants were more likely to feel that the quality needed to improve than more highly educated participants.

There were no further correlations with any other demographic variables (age: $r(43) = .291, p > 0.05$; health status: $r(43) = 0.021, p > 0.05$; time since diagnosis: $r(40) = .051, p > 0.05$; internet usage: $r(43) = -.065, p > 0.05$; OHI usage: $r(43) = -.250, p > 0.05$). A Mann-Whitney test was also run to compare the mean scores for this question between males and females. The results showed no significant difference in the means or the two gender groups ($U(43) = 242, p > 0.05$). The qualitative data provided by additional comments to this question showed that a number of participants were aware of the importance of quality appraisal skills in order to effectively discern OHI quality:

“The internet is un-moderated so anyone can write any old rubbish! But it's up to the reader to discern how useful it is.”

Other common themes throughout the qualitative data for this question included participants noting what they perceived to be negative information attributes, such as non-UK based information and OHI from companies advertising products:

“Lots of sponsored info on the net (from USA) (Too Much!!)”

Whilst one further participant showed specific concerns about the currency of OHI, another expressed their frustration at not having access to academic journal articles. Another response showed that, although they felt OHI did need to improve, they had concerns about the possibility of organisations censoring the web:

“I cannot think of an organisation that I would trust to censor the web.”

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Perceived ability to assess OHI quality

Further quantitative data states that only 56.8% (n=25) of participants felt able to accurately assess the quality of OHI. A test for homogeneity (Mann-Whitney) showed that the mean highest educational level was significantly higher for those who felt that they could accurately assess the quality of OHI (U(42) 111.5, $p < 0.01$). Further tests for homogeneity showed that, although those who perceived themselves as being able to assess OHI quality were significantly more likely to be higher level internet users than those who did not perceive themselves to have this ability (U(42) 143.5, $p < 0.05$), there was no difference in the mean OHI usage for the two groups (U(42) 162.5, $p > 0.05$).

Further Mann-Whitney tests showed no significant differences in the means for any other demographic variables for those who did and those who did not perceive to be able to assess OHI quality (time since diagnosis: U(39) 193.5, $p > 0.05$; health status: U(42) 174, $p > 0.05$; age: U(42) 182, $p > 0.05$). A non-parametric correlation between binary variables (phi coefficient) was also run and showed no relationship between whether individuals felt able to assess OHI quality or not and gender ($\phi(42) -0.19$, $p > 0.05$).

Quality assessment criteria

Data from open-ended questions aided the discovery of specific criteria used by participants to help assess OHI quality. These included a number of themes that had already been identified and discussed in previous qualitative questionnaire data, such as information currency, accuracy, transparency of sources and authorship.

Participants also went into more specific detail about authorship, noting a need to consider the possible financial motivations of OHI authors and the companies that they are associated with. Some participants also showed awareness of the overall quality of the writing and the tone in which the website was written:

“Is it a rant? Opinion? Etc.”

Others noted that they judged quality based on whether or not the information provided a balanced view of the topic that it was covering. Further popular criteria for quality assessment identified in the qualitative data were the simplicity or clarity of

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the website and how concise and easy it was to navigate. In addition to this, one participant mentioned that they would consider the number of pages within the site when assessing quality. Preferences in terms of websites were also mentioned, with some participants stating that they prefer academic, professional or UK-based sites.

In addition to quality assessment criteria, a small number of participants also identified specific information appraisal skills that they felt they used to help them assess OHI quality. These skills included using common sense or intuition and cross-checking information. Overall, the information appraisal skills cited by participants seemed to vary between general and basic considerations to a more complex set of criteria:

“Does it fit with my existing knowledge/experience? Does it claim to be the answer to everything? Is there any risk involved in trying it out? Are they trying to sell me something?”

Quality assessment interventions

Participants were also asked what they felt would increase their ability to assess the quality of OHI. A number of potential improvements to OHI were suggested that could help increase participants' abilities to assess the quality of OHI. These included fuller indexes, better links between sites and the inclusion of comments/ratings. Other previously mentioned interventional themes reappeared, such as simplicity/clarity, transparency, less information being available from vested interests, better quality of writing and access to specialist information.

One participant specifically felt that ‘smarter searching’ would be helpful in allowing them to effectively assess OHI quality:

“Clearer indication of bona fides in the search engine snippets, and/or a smarter choice by the search engine of its priorities.”

Other patients mentioned personal barriers that, if lifted, may increase their ability to assess OHI. These included experience/knowledge of OHI and functional problems. Another common theme was the need for assistance from others in order to accurately

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assess quality. While one participant suggested general assistance, others mentioned that help from their healthcare professional/surgery would also be useful:

“Benefit from guidance by healthcare professionals and written information leaflets with recommended sites. And cautionary advice regarding the use of other sites.”

One participant seemed content with their ability to assess the quality of OHI and suggests:

“I discuss with other people (members of online support groups and sometimes healthcare professionals) and I think that’s all I need.”

Summary

Results showed that, despite the majority of OHI users agreeing that it was easy to find useful and relevant OHI, the majority also agreed that the quality needed to improve. A number of participants also noted the need for quality appraisal skills in assessing OHI. Respondents demonstrated concerns about non-UK information, OHI from companies or sponsored information, how up-to-date the information was and lack of access to academic papers regarding health. The majority of participants felt able to accurately assess the quality of OHI. This majority tended to be more highly educated and used the internet more frequently. Quality assessment criteria cited by participants included currency, accuracy and transparency of sources.

Objective 3: Find out how people use OHI after they locate it

Quantitative data was collected through the stage one questionnaire in order to ascertain how people used OHI after it had been located and the extent of information sharing within social networks.

How people use OHI

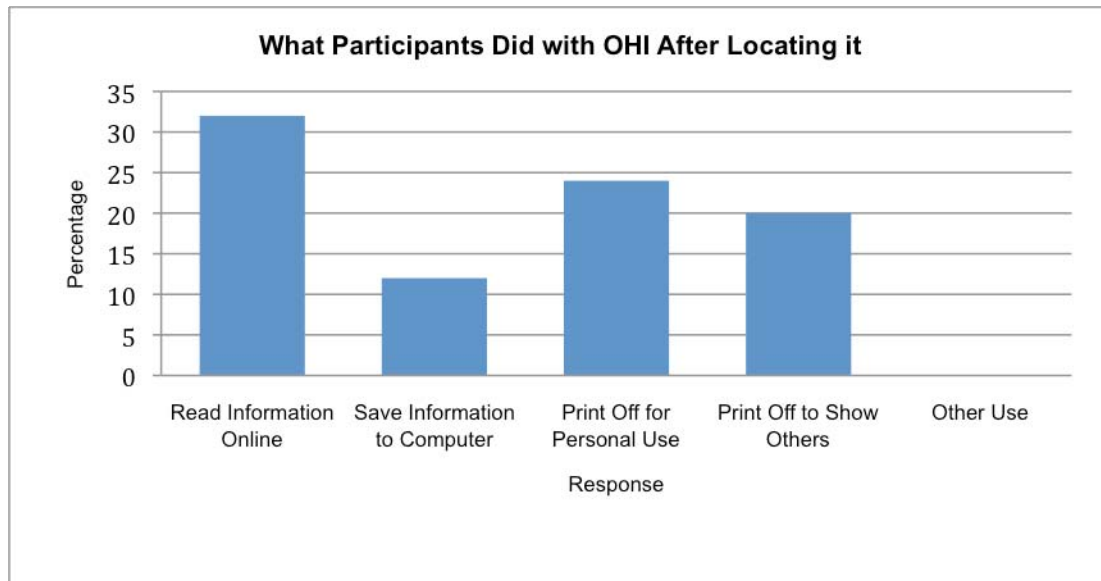


Figure 12. What participants did with OHI after they located it.

Participants were provided with multiple-choice optional answers to the question ‘What do you do with online health information after you have found it?’ and were asked to select as many options as applied. Figure 12 shows that 71% (n=32) of participants stated that they read the information online, while 53.3% (n=24) printed it off for their personal use, 44.4% (n=20) printed it off to show others and 26.7% (n=12) saved it to their computers. Although participants were provided with space to specify other ways in which they used OHI, no additional information was provided.

How individuals share OHI

The 44.4% (n=20) of participants who stated that they shared OHI with others were asked with whom they were sharing. Results demonstrated that patients shared with peers with the same chronic illness, health professionals, and friends and family.

A number of Mann-Whitney tests were conducted in order to ascertain the differences in mean scores on demographic variables between those who did and those who did not print off OHI to show others. Results from these tests showed that participants who printed off OHI to show others were more likely to be more highly educated (U(43) 134, $p < 0.01$), be high-level OHI users (U(43) 160.5, $p < 0.05$), younger (U(43) 144, $p < 0.05$) and have higher perceived health status (U(43) 161, $p < 0.05$).

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Summary

Participants noted doing a range of things with OHI after it was located, including reading the information online, saving it and printing it off for personal use or to show others. Those who showed others admitted sharing the information with peers with the same chronic illness, family members, healthcare professionals and friends. OHI sharers were more likely to be younger, better educated, use the internet more often, and have higher perceived health status than those who did not.

Objective 4: Consider how participants perceive that others respond to them as information-enabled patients

The fourth objective of the study was to ascertain how participants perceived the reactions that they had encountered from others to their OHI-seeking behaviour. Participants were asked to provide qualitative data through open-ended questions about their general experiences. They were also asked both qualitative and quantitative questions about the reactions that they had encountered specifically from health professionals.

Perceived reactions from others

Primarily, participants were asked to answer the question ‘In your experience, how have people reacted when you show them health information that you have found online’. A range of experiences were documented by respondents, with a number of participants noting that they had experienced a variety of different reactions from individuals:

“Sometimes with interest, sometimes with scepticism, sometimes with shock and anger that this information wasn’t made available to them by their health-care professional.”

The positive responses outlined by participants included individuals showing general interest in their OHI seeking, the information located provoking further discussion, encouraging supportiveness between individuals and, in one case, leading to a request for help with OHI seeking from another person. As well as citing scepticism and shock as negative examples of reactions experienced from others, participants also noted encountering concerns about cost and the subjectivity of OHI, as well as

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apprehension about the lack of a guarantee. In addition to the aforementioned positive and negative experienced reactions, one participant specifically noted that they felt people were “unsurprised” by his OHI-seeking behaviour.

Reactions from health professionals

In order to quantify the reactions from health professionals as perceived by their patients, respondents were asked to what extent they agreed with the statement ‘In my experience, health professionals react positively to me bringing OHI into the consultation’.

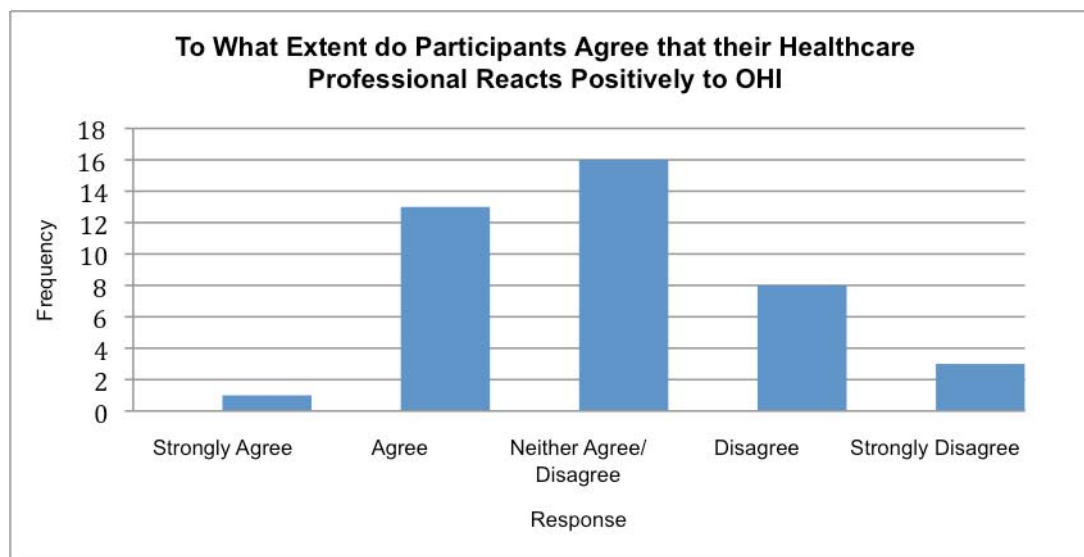


Figure 13. The extent to which participants agree that their healthcare professional reacts positively to OHI.

Figure 13 shows that 34.1% (n=14) of participants either agreed or strongly agreed with the statement (31.7% agreed (n=13); 2.4% (n=1) strongly agreed) whilst 26.8% disagreed or strongly disagreed (19.5% (n=8) disagreed; 7.3% strongly disagreed (n=3)). In order to provide a greater depth of data regarding the perceived reactions of health professionals to OHI seeking, respondents were asked to justify their answers to the above question. Individuals who explained that they felt that health professionals reacted positively to their information-enabled status felt that OHI would help increase the health professionals’ awareness of certain issues, that the health professionals would benefit from more informed patients who would ask informed questions, that it would assist in time saving and that it would help develop a potentially desirable partnership relationship between patient and caregiver. Those

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who felt health professionals did not act positively attributed it to the breakdown of traditional paternalism, health professionals' general lack of appreciation for OHI, health professionals feeling undermined and OHI quality concerns:

“If I did I would feel like it would undermine consultants' ability.”

One participant who had previously worked within the field of health and social care explained how her previous experiences had affected her perception of health professionals' reactions to OHI seeking:

“I do not present sheets of paper as I have observed (from practice) the reactions of doctors to patients who have done this.”

The participants' responses to this question also provided potential theories about the variations in reactions from health professionals. Respondents particularly noted how the patients' approach to sharing OHI with a health professional, and their existing relationship, had a potential effect on the perceived reaction encountered from the professionals.

One participant also noted that they felt their health professional reacted positively because the information that they shared with them allowed them to become more informed:

“They seem ill-informed about current thinking and research regarding my illness – raises their awareness.”

A number of non-parametric correlations (Spearman's rho) were run in order to assess if there was a relationship between whether individuals perceived health professionals as reacting positively to them bring OHI into the consultation, and the demographic variables. Results demonstrated no relationships between their responses and any demographic variable (age: $r(39) = -.225, p > 0.05$; education: $r(39) = .049, p > 0.05$; health status: $r(39) = .277, p > 0.05$; time since diagnosis: $r(36) = .247, p > 0.05$; net usage: $r(39) = .058, p > 0.05$; OHI usage: $r(39) = 0.004, p > 0.05$). In addition, a Mann-Whitney test was run to see if the mean scores for perception of health professionals' reactions varied

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significantly between males and females. Results showed no significance in the differences in the means of the two gender groups ($U(39) 185.5, p>0.05$).

Summary

Respondents documented a number of reactions from peers. Positive reactions included general interest, provoking further discussion, supportiveness and, in one case, a request for help with OHI seeking from another person. Negative reactions included shock, scepticism, concerns about cost and the subjectivity of OHI, as well as apprehension about the lack of a guarantee. Participants also noted that they had also experienced a range of reactions from health professionals to them bringing OHI into the consultation. Those who had experienced positive reactions felt that health professionals behaved in this way in order to encourage a partnership approach, to save time and to ensure that they were fully informed. Those who had experienced negative reactions attributed it to the breakdown of traditional paternalism, health professionals' general lack of appreciation for OHI, health professionals feeling undermined and OHI quality concerns.

Objective 5: Find out about the effects of OHI seeking and how it influences healthcare decisions

The final objective of the stage one questionnaire was to establish the effect of OHI seeking for the participants involved. This included the consequences for patient–practitioner interactions, and its effect on confidence levels and healthcare decision-making.

Effect on consultations with health professionals

Quantitative data was collected in order to ascertain to what extent respondents agreed with the statement 'Bringing online health information with me improves my consultations with health professionals'.

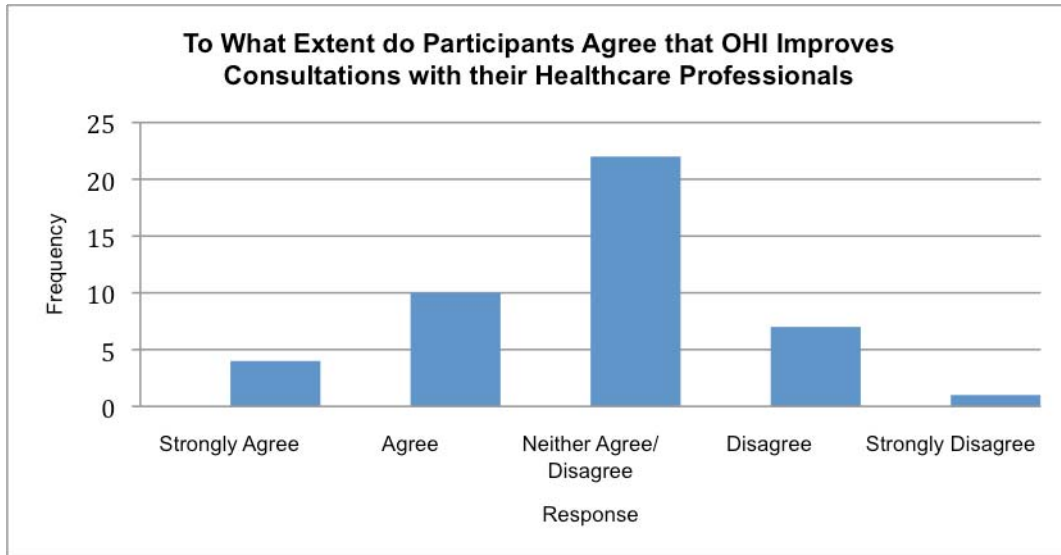


Figure 14. The extent to which participants agree that OHI improves consultations with their healthcare professionals.

Figure 14 shows that 31.8% (n=14) either agreed or strongly agreed with this statement (22.7% (n=10) agreed; 9.1% (n=4) strongly agreed), while 18.2% (n=8) either disagreed or strongly disagreed (15.9% (n=7) disagreed; 2.3% (n=1) strongly disagreed). The remaining 50% (n=22) stated that they neither agreed nor disagreed with the statement. A number of non-parametric correlations (Spearman’s rho) were run in order to ascertain whether any significant relationships existed between the responses for this question and the demographic variables. The further analysis showed no relationship between participants’ answers to this question and demographic information (age: $r(42) .020, p>0.05$; education: $r(42) -.104, p>0.05$; health status: $r(42) .205, p>0.05$; time since diagnosis: $r(39) .05, p>0.05$; internet usage: $r(42) -0.05, p>0.05$; OHI usage: $r(42).187, p>0.05$).

However, there was a strong positive correlation between responses to whether OHI improves consultations and whether participants felt that health professionals reacted positively to their OHI ($r(39) .527, p<0.01$). A Mann-Whitney test for homogeneity was also run in order to ascertain whether there was a difference in the mean scores for perception of whether OHI improves consultations for males and females. Results showed no significant difference in the mean scores for males and females ($U(42) 196, p>0.05$).

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Respondents were asked to provide additional comments to this question in order to develop the understanding of the rationale behind their quantitative answers, and to expand on the existing responses. Participants noted a range of positive and negative implications of bringing OHI into a consultation with a health professional. The following statement explains that, although the experience has the potential to be a positive one, it depends very much on the nature of the health professional:

“It improves my health and gets results, but harms the patronising/paternalistic relationship. So if they can’t move on, it’s harmful – and does not improve the consultation.”

Another participant noted the importance of the health professionals’ reaction to them bringing OHI into the consultation, and expressed that they would discontinue a relationship with a health professional who reacted adversely to them bringing OHI into the consultation.

While the previous statements implied the importance of the nature/manner of the health professional, another participant response suggested that the role of the patient was also imperative in ensuring positive outcomes:

“There is a narrow line between stimulating general interest and discussion and appearing to be the smart ass who seems to be challenging the professional.”

The notion of a traditional paternalistic hegemony that exists between patient and health professional and the possibility of practitioners feeling “undermined” were themes within participant responses. Respondents also noted perceiving that health professionals potentially may have concerns about OHI quality.

Confidence in decision-making

Participants were asked to state whether they agreed that OHI seeking made them feel more confident about making decisions regarding their health care. Results showed that a majority of 71.4% (n=30) agreed that OHI did have this effect. A number of statistical tests (Mann-Whitney) were conducted in order to compare the means of the

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demographic data for those who agreed and those who disagreed with the statement that OHI seeking made them feel more confident in making decisions regarding their health care. The results from the additional statistical analysis showed that participants who agreed with this statement were likely to be younger ($U(40) 69.5$, $p < 0.01$), more educated ($U(40) 65.5$, $p < 0.01$), and more frequent internet ($U(40) 93.5$, $p < 0.05$) and OHI users ($U(42) 93$, $p < 0.05$). Further tests for homogeneity showed there was no relationship between the responses to this question and health status ($U(40) 122$, $p > 0.05$) or time since diagnosis ($U(37) 138.5$, $p > 0.05$). Two additional tests (phi coefficient) were conducted to show whether there was a relationship between participants' answers for the above question and their gender, and whether they felt health professionals reacted positively to their OHI (binary variables). Results showed no relationships between whether individuals agreed that OHI seeking made them feel more confident about making healthcare decisions and gender ($\phi(40) -0.45$, $p > 0.05$) or whether health professionals reacted positively to them bringing OHI to the consultation ($\phi(37) .337$, $p > 0.05$).

Respondents who agreed that OHI seeking made them feel more confident about making healthcare decisions were asked to provide an explanation to why this was the case. Reasons included OHI seeking providing them with increased feelings of control, allowing them a link to others in a similar position, assisting them in researching treatment, helping them gain a "second opinion", aiding discussion, allowing them to research at their own pace and encouraging a partnership relationship between patient and practitioner. In addition to the above reasons, patients also felt that taking responsibility for their health care in the form of OHI seeking would increase the level of respect that their health practitioners had for them:

"If a healthcare practitioner perceives a patient as intelligent and informed and self-motivated, s/he is more likely to treat the patient seriously (as a fully paid up member of the human race) and may engage in a partnership dialogue (instead of ticking the box, issuing platitudes and moving on)."

Participants who did not agree that their OHI-seeking behaviour made them feel more confident in making healthcare decisions were also asked to provide details about why they felt this to be the case. Responses included participants having doubts about

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their appraisal skills and the overall quality of the information, and not wanting to come across as a ‘know it all’. It was also noted that some participants wished for the health professional to remain as the decision-maker, thus reinforcing the traditional model of health care. Another participant also expressed the importance of face-to-face interaction with their health professional in order to make healthcare decisions.

Finally, participants were asked to specify how OHI had helped them make decisions about various aspects of health care. Figure 15 shows 57.8% (n=26) of participants stated that they used OHI to choose their medication or treatment, while 33.3% (n=15) used it to join support groups, 15.6% (n=7) used it to find healthcare providers and 15.6% (n=7) used it to make other decisions.

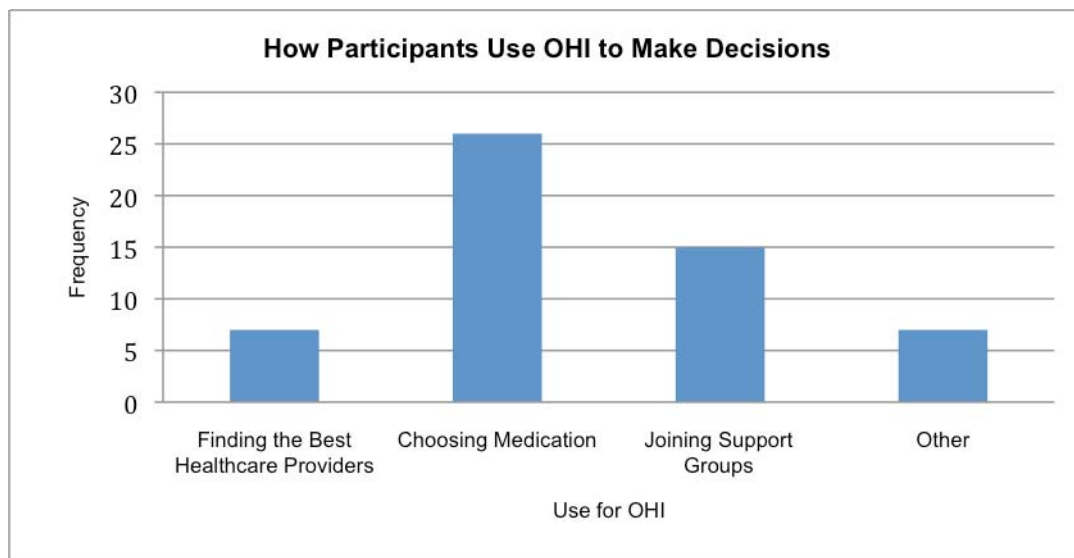


Figure 15. How participants use OHI to make decisions.

Confidence in discussing health and treatment

Participants were asked to state whether they agreed that OHI seeking made them feel more confident in discussing their health and treatment regimes with health professionals. Results showed that a majority of 62.8% (n=27) agreed with this statement. A number of statistical tests were conducted (Mann-Whitney) to compare mean scores for the demographic variables of the two groups. The results demonstrated that individuals who agreed that OHI made them feel more confident about discussing their health care with health professionals tended to be younger (U(41) 116, $p < 0.05$), more highly educated (U(41) 110.5, $p < 0.01$) and higher internet (U(41) 132, $p < 0.05$) and OHI users (U(41) 87, $p < 0.01$). They also tended to feel that

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OHI improved their consultations ($U(40) 106, p < 0.01$). There was no relationship between whether OHI made participants more confident in discussing their health with health professionals and health status ($U(41) 155, p > 0.05$), time since diagnosis ($U(39) 194, p > 0.05$) or whether health professionals reacted positively to OHI ($U(38) 152.2, p > 0.05$). Two phi correlations were run in order to ascertain if there was a significant relationship between participants' responses to this question and other binary variables (whether they felt OHI helped them make healthcare decisions and gender). Results showed that there was a highly significant positive relationship between whether or not OHI makes individuals feel more confident discussing their health and treatment with professionals, and whether or not it allows them to make healthcare decisions ($\phi(38) .787, p < 0.01$). There was no significant relationship between confidence in discussing issues and gender ($\phi(41) -.263, p > 0.05$).

Summary

Participants demonstrated a range of perceptions regarding whether OHI improved their consultations with health professionals. Those experiencing positive reactions from their health professionals were more likely to agree that OHI improves consultations. Participants stated that the ability for OHI to improve consultations depended on the practitioners' attitude and the manner in which the patient shared the OHI. The majority of participants also agreed that OHI helped them feel more confident in making decisions about their health care. Those who agreed were more likely to be younger, more highly educated and higher OHI and internet users than those who did not agree. The majority of participants also felt that OHI made them feel more confident in discussing their health and treatment with professionals. Those who agreed with this tended to be younger, more highly educated, higher level OHI and internet users, and agreed that OHI improved consultations more than those who disagreed. Finally, individuals who agreed that OHI made them feel more confident discussing their health and treatment with professionals were more likely to state that OHI also helped them make healthcare decisions.

Chapter 7. Stage Two Methods

Introduction

As outlined in the previous methodology chapter, a mixed-methods approach was adopted within this research project in order to effectively tackle the complex nature of the phenomena under study. This approach allowed for pragmatic development of the study's methods based on its aims and objectives, and ultimately resulted in the development of a two-stage research design (see previous methodology chapter). As previously stated in the preliminary methods chapter, the foremost of these stages (stage one) had two main purposes that contributed to fulfilling the study's aims. The first of these was to provide a breadth of knowledge around how individuals with chronic illness operate as online health information (OHI) seekers (see stage one methodology). The second aim of stage one was to provide specific knowledge that would help identify the interesting phenomena from within the research area, and assist in formulating research questions based around an appropriate and relevant phenomenological focus that can be studied in depth within the stage two interviews. It was for this reason that a number of open questions were included alongside the closed-format questions within the stage one data collection tool, to not only complement and allow for elaboration of the quantitative data, but also prevent limiting the possibility of emerging phenomena and allow for a level of induction to occur within a predominantly deductive research tool. Therefore, the results from stage one of the study would be able to effectively inform the focus of stage two, providing a level of methodological cohesion that entwines the two stages and accurately reflects the adoption of a mixed-methods approach as opposed to a multiple methods research design.

Although developing the phenomenological focus for research by using a preliminary and principally quantitative study was innovative, the idea of achieving a breadth of understanding prior to an experience-based study in order to uncover a relevant and interesting phenomenon for research is echoed within phenomenological philosophy. Van Manen describes the process of orienting to the phenomenon prior to formulating the phenomenological question (Van Manen, 1990). This process depicts the researcher focusing carefully on the question of what possible human experience is to be made topical for phenomenological research. In the same way, Van Manen describes the formulation of the phenomenological question by identifying an area of

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topical interest based on an individual's orientation. This concept can also be witnessed being utilised in a more conventional way than proposed in this study within existing phenomenological research, in order to effectively handle the complexity of phenomena within the field of health and social care. In their 2005 paper on the experience of intimate caring for a loved one with Alzheimer's disease, Todres and Galvin used two different methods within the same (qualitative) paradigm in order to achieve both breadth and depth to their research (Todres and Galvin, 2005). They describe using a qualitative stage one 'grand tour' interview in order to generate a broad thematic understanding of the caring narrative to provide the study with a breadth of information. They identified that this study not only had value in its own right, but also provided a valuable focus for stage two, in much the same way as is suggested by the current research design. The large difference between the current study and the aforementioned is that Todres and Galvin operated within a single paradigm, whilst the current study utilises both quantitative data collection, with its roots within the positivist paradigm, and qualitative research techniques, with its roots within the interpretivist paradigm.

As previously noted within the stage one methodology chapter, this study was designed to analyse qualitative and quantitative data separately, using techniques that honour the epistemological differences between paradigms and only combine the findings within the discussion in order to provide a more complete picture of the research area from different viewpoints. In addition, the qualitative and quantitative techniques have been used throughout this study to answer separate research questions within the overarching research aim and therefore was not combined for the purpose of triangulation through cross-validation. The mixing is provided through the cohesion between stages and joint discussion as opposed to the muddling of different methods that differ epistemologically. Figure 16 explains how the two stages of the study worked together in order to develop a cohesive mixed-methods study that provided a breadth and depth of information regarding the research area:

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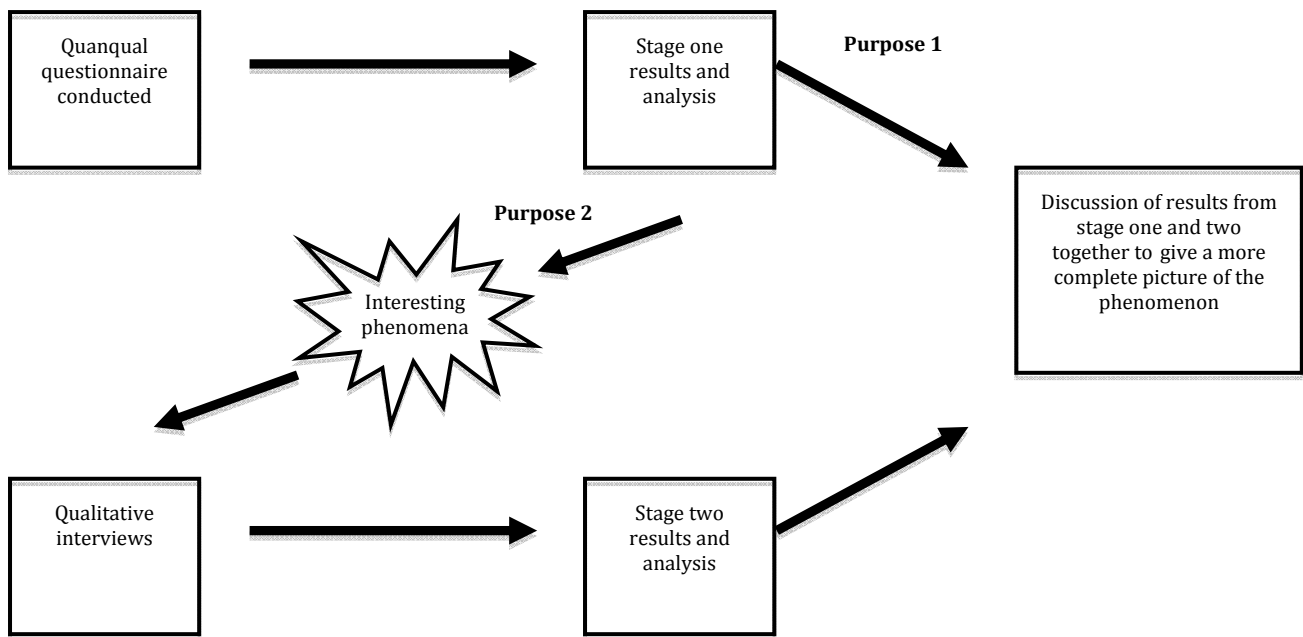


Figure 16. The cohesion between stages one and two

The Phenomenological Method

Phenomenology as a research tradition emerged within the early part of the 20th century and was built upon the work of earlier philosophers who discussed human experience as a starting point for philosophy. During the 20th and early 21st centuries, a number of attempts have been made to define phenomenological philosophy in a way that can be understood by those with or without a background in philosophical thought. One of the most recent and easily comprehensible definitions is provided by Giorgi:

Phenomenology as a philosophy seeks to understand anything at all that can be experienced through the consciousness one has of whatever is “given” – whether it be an object, a person, or a complex state of affairs – from the perspective of the conscious person undergoing the experience. (Giorgi, 2009), p.4)

In other words, the aim of phenomenological philosophy is to develop a greater understanding of individuals’ experiences through the consciousness of the experiencer, as opposed to analysing the ‘given’ in an objectivistic manner that

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excludes the individual experiencing it (Giorgi, 2009). By adopting this approach, the theory is that it will allow human beings to be understood from ‘inside’ their subjective experience (Todres and Holloway, 2006). Therefore, the main emphasis of phenomenological research is to describe or interpret human experience as lived by the experiencer in a way that can be utilised as a source of qualitative evidence. The preliminary concern for the researcher is to use qualitative data collection techniques to obtain examples of everyday experiences. Edmund Husserl (1859–1938), who is credited as the founder of phenomenology in the modern sense of the term (Spiegelberg, 1994, Giorgi, 2009), developed the work of Wilhelm Dilthey (1833–1911) on the nature of individuals’ engagement in experiential life. Husserl identified what has gone on to become the subject matter of all phenomenological research – the life-world (Todres and Holloway, 2004), which is also referred to by some phenomenologists as the ‘lived experience’. According to Husserl, by focusing on a specific lived experience in a number of variations, it is possible to identify insights that are common throughout experiences and that can be applied more generally beyond the cases within the study in order to emphasise the common themes held within the lived experience. These commonalities are also known as essences or essential structures and help describe the common features of an experience. Within this study, the revelation of essences has important implications with regard to understanding commonalities in experience in a way that has the potential to be used to effectively educate and inform individuals. By understanding the common features of the experience of seeking OHI, crucial information is presented that has the potential to inform and enlighten health professionals in understanding the lived experiences of their existing and potential patients. I will now continue my description of the phenomenological method by first explaining the two main ways that the phenomenological tradition is interpreted in terms of methods.

Streams of phenomenology

It is important to note at this stage that, although all phenomenological research is based on the same rich philosophy concerning understanding human experience, it can be separated into two main streams: descriptive (eidetic) phenomenology, which draws more heavily on the work of Husserl and, more recently, Giorgi; and interpretative (hermeneutic) phenomenology, drawing on the work of Martin Heidegger (1889–1976) and later Van Manen. As the names suggest, unlike

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interpretive phenomenology, descriptive phenomenology is focused less on the interpretations of the researcher and more on the descriptions of participants' individual experiences (Cresswell, 2007). Whilst within interpretive phenomenology the researcher provides an interpretation of the experiencer's lived experience, descriptive phenomenologists would argue that, without direct access to the individuals' stream of consciousness, it is impossible to do more than merely describe the life-world because the exact meaning for that individual outside their own consciousness can never be fully understood. In addition to this, descriptive phenomenology lays greater focus on the Husserlian concept of entering into the phenomenological attitude and regarding everything from the perspective of consciousness as opposed to assuming the natural attitude. Put simply, this involves looking at all objects from the perspective of how they are experienced, regardless of whether or not they actually are the way they are being experienced (Giorgi, 2009). This attitude is obtained through a process of 'bracketing' in which researchers attempt to withhold their preconceptions so that they can approach the phenomenon to be studied with 'fresh eyes' and achieve a sense of 'openness'. I will now provide a theoretical example of how bracketing could be used in the current research study:

The individual being interviewed describes a situation in which they were faced with a large amount of OHI being returned from a search conducted using a popular search engine. The interviewer has recently read in an academic article that being faced with large amounts of OHI is a negative experience because the individual can struggle to navigate large amounts of OHI effectively. The interviewer needs to be careful not to influence the interview or analysis in the direction of what they have read. This experience may have been being described as a positive experience in which the individual is presented with a wealth of information; therefore, making assumptions based on previous knowledge would lead to the researcher moving away from the phenomenological attitude. During descriptive phenomenology, the researcher has to bracket their past knowledge and keep an open mind in order to ensure that they can describe the experience the way that it was lived by the experiencer.

After the researcher has assumed the phenomenological attitude and successfully gathered life-world descriptions of personal experiences, each transcription is now at

the stage where meanings can be uncovered using a phenomenological method for analysis.

Justification

A phenomenological approach was adopted in order to provide a depth of focused experiential data based on specific phenomenological questions, as opposed to providing a depth of more general open-ended qualitative data. Specifically a descriptive phenomenological approach was utilised (as opposed to an approach associated with interpretive phenomenology) in line with the belief that interpretations regarding an individual's experiences cannot be made without direct access to that person's stream of consciousness. In other words, without knowing explicitly how the experience was inferred within the individual's own consciousness, it could be argued that it is impossible to make accurate interpretations of the specific meaning of their experiences. Therefore in order to offer a more philosophically sound approach to experiential research, a descriptive phenomenological approach was adopted in the current study.

Giorgi and colleagues (Giorgi, 1985, Giorgi and Giorgi, 2004, Giorgi, 2009) have developed a systematic procedure for analysing descriptive phenomenology that has become popular with researchers within and beyond the psychological discipline, such as nurses, sociologists and anthropologists.

Giorgi's descriptive phenomenological method in psychology

This method takes a systematic approach to descriptive phenomenological analysis and outlines a number of stages that must be conducted in order to achieve a full descriptive phenomenological analysis. These are:

- Obtaining rich life-world descriptions
- Reading the transcriptions thoughtfully in order to get a narrative sense of the text as a whole piece
- Dividing the descriptions up into units, signifying changes in meaning – 'meaning units'
- Expressing the sense of each meaning in a general manner

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- Developing a 'structure' that integrates the common meanings throughout all life-world descriptions
- Opening out the structure and elaborating on the common themes from within by using original participant data to develop the richness of the analysis. It also provides an opportunity to discuss the unique ways that each theme was experienced by participants.

The application of this method to stage two data will be discussed in further detail within the research procedure section.

Research Design

Stage two focus

Subsequent to the analysis of stage one findings, a number of emerging themes were identified within the data that were considered possible areas for future experience-centred qualitative research. In order to assess which of the potential phenomenological foci would be the most justified and appropriate, a further, more specified, literature search was conducted and presented alongside a statement of justification based on stage one findings. These justifications were then assessed in order to gauge which identified theme would be the most appropriate and rich focus for stage two of the study. This assessment was primarily conducted by myself, and the decision was then reviewed by my PhD supervisors to ensure that the most essential and justified focus was adopted for stage two. After much consideration, it was decided that, based on the relevant literature and stage one findings, the experience of OHI seeking for older adults would provide the most justified and appropriate focus for the phenomenological stage of the study. The following section will outline the background literature and stage one data that contributed to this decision.

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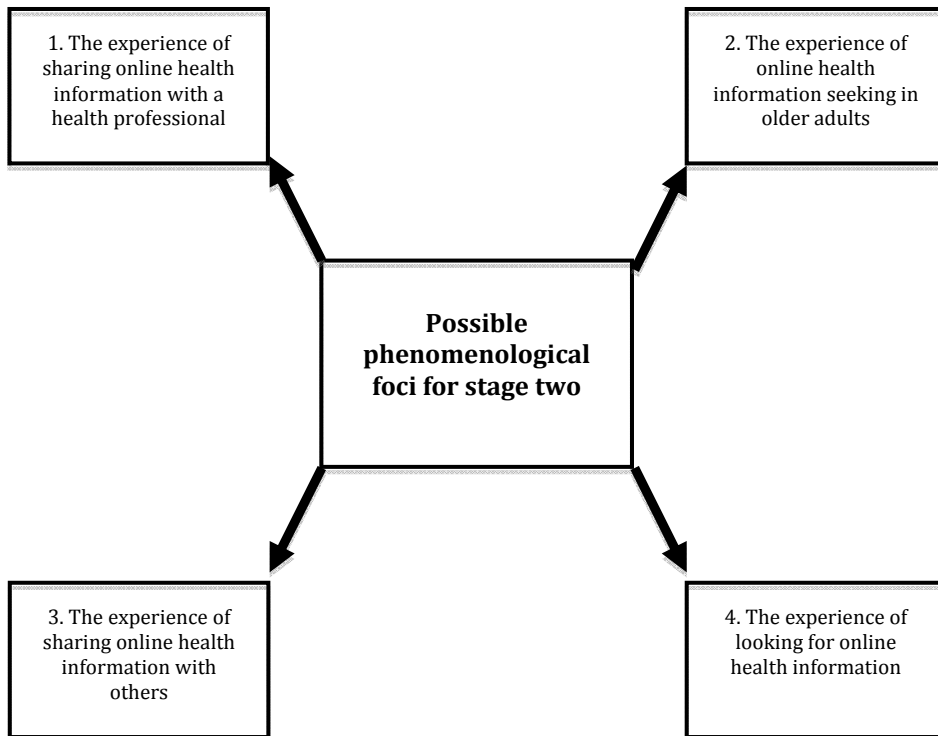


Figure 17. Possible phenomenological foci for stage two.

Deciding on the phenomena to be studied

The internet has the potential to provide an extraordinary opportunity for the older generation living with chronic illness to access useful and relevant OHI. Its possibilities are especially great for older adults who are homebound or live in remote areas as it may be difficult for them to access health information by more traditional means (Becker, 2004). It could also have positive implications for the significantly higher than average number of older adults who live with some form of disability, which creates an additional barrier to accessing traditional forms of health information (U.S. Department of Health and Human Services, 2002).

Although the potential for older adults to use the internet to seek health information is clear, previous research in this field indicates that this potential is not yet being fully realised (Brodie et al., 2000, Cotten and Gupta, 2004, Office of National Statistics, 2007, Office of National Statistics, 2008, Office of National Statistics, 2009). Most recently, UK National Statistics have shown that adults aged 65+ years were the least likely to use the internet, with 66.5% stating that they had never used it at all. However, access by those aged 65+ years increased proportionally by 15% (30%–34.5%) compared with an increase of only 3% in the 16–24 years age group (Office

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of National Statistics, 2009). Although it is clear that older adults are less likely to use the internet than other age groups, there are still unanswered questions regarding the adoption or non-adoption of OHI within the older population.

Previous research has indicated that the experience of OHI seeking may be very different for the older generation compared with younger age groups (Brodie et al., 2000, Becker, 2004, Turner et al., 2007). This could be explained partially by the barriers that affect this age group, such as physiological issues, lower levels of education and literacy, and attitudinal issues.

Physiological issues such as vision, cognition and physical impairments are more likely to affect the older population (Becker, 2004) and therefore affect web usability and the OHI experience of older adults. In addition, older adults living with chronic illness are even more likely than other groups of older adults to encounter these barriers, thus potentially affecting their OHI-seeking experiences to a greater degree.

There are also attitudinal issues that may have an effect on the OHI-seeking experience of older adults (Wilfong, 2006). These include perceived relevance, usefulness and usability (Olphert et al., 2005), orientation towards the past or future (Blit-Cohen and Litwin, 2004), and perceptions of ability to learn new skills as aging takes place. All these factors have not only been seen to affect the experiences of older people using the internet, but have also been recognised as playing an important part in whether older adults opt in to the information age (Turner et al., 2007).

Turner et al. (2007) specifically described how older people account for their experiences with interactive technology. Along with common themes such as alienation, identity, agency, anxiety and time, Turner et al. presented the theme of older adults feeling that they were 'too old' for computers (Gustafson et al., 1998, Stanley, 2003, Turner et al., 2007). These studies showed that older individuals perceived that their age rendered them incapable of learning how to use new technology (Stanley, 2003).

Orientating the stage two focus in this way involved conducting a phenomenological study into the specific experiences of older adults seeking OHI. By gaining a more in-

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depth understanding of OHI-seeking experiences for this sub-group, suggestions can be made on future research into how older adults may be facilitated into engaging with new online health technologies in order to prevent further disadvantage in contemporary society.

Justification from stage one results

Statistical tests run on the non-parametric numerical data from stage one provide justification for further study into the relationship between age and OHI-seeking experiences for this sample. The average age of participants in the internet usage group was 56.42 years compared with 69.13 years for the internet non-usage group. When statistically analysed, these results showed that the non-usage group has a significantly higher mean age than the usage group ($U(518.5)$, $p < 0.01$, $n=100$); therefore, within this sample, older participants were less likely to be internet users than their younger counterparts. The qualitative analysis of the stage one open-ended questions gave depth to this quantitative finding about age and OHI seeking. When the non-usage participants were asked why they had never used the internet, one of the key themes that arose was age. One participant explained:

“Do not possess a computer and at my age see little point in having one.”

Two additional respondents explained that they felt they were “too old” to use the internet, confirming previous findings by the aforementioned studies (Gustafson et al., 1998, Stanley, 2003, Turner et al., 2007).

Age did not have a significant relationship with level of usage between internet users ($r(-.245)$, $p > 0.05$, $n=45$), although it did with OHI usage ($r(-.340)$, $p < 0.05$, $n=45$). This shows that, although age isn't related to the amount of general internet usage for users, older participants are less likely to use OHI more regularly compared with younger respondents. Statistical analysis also showed that there was a relationship between age and whether seeking health information made participants feel more confident to make healthcare decisions ($U(69.50)$, $p < 0.01$, $n=42$); therefore, older participants were less likely to feel that OHI seeking increases confidence in decision-making. In addition, there was a relationship between age and whether OHI seeking made participants feel more confident about discussing their health and treatment

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regimes with health professionals ($U(116)$, $p < 0.05$, $n=43$); therefore, older participants were also less likely to feel that OHI seeking increases confidence in discussing their health and treatment with health professionals.

As mentioned in the literature (Brodie et al., 2000, Becker, 2004), our sample also reflected that older adults were more likely to be less educated ($r(-.456)$, $p < 0.05$, $n=43$), which may affect the OHI-seeking experience because education has been seen as an additional barrier to OHI.

The stage one data used to justify the focus of stage two will be used alongside the qualitative findings within the discussion to help provide a holistic picture of the experience of older adults with a chronic health condition seeking OHI. It is important to note at this stage that, in line with the philosophical approach of the study, although stages one and two view the same area of study, they each look at separate phenomena within the research area. While stage one asks questions predominantly focused on understanding ‘the measure of how adults with chronic health conditions are operating as online health information seekers’, stage two focuses on the ‘lived experiences of older adults with chronic health conditions seeking OHI’. Therefore, the nature of stage two questions will be experience orientated and discovery led.

Once the focus for stage two of the study had been identified, a statement of objectives was developed to inform the further development of the stage two research design.

Research Aims and Objectives

The aim of the second stage of the research project was to explore, in a detailed way, how the experience of searching for OHI became a meaningful activity for older adults living with chronic illness. This objective was refined to include the focus on older adults in line with stage one findings (see above). This exploration into meaning allowed for the development of a deeper insight into the nature of the experiences of older adults seeking information relating to health online, and presented both the shared and unique meanings that arise from OHI seeking. The findings from the second stage will provide the study with greater depth and produce qualitative findings that can not only be used alongside stage one data to provide a rich

description of the phenomenon, but can also identify commonalities in experience that can be used in a practical way to inform training and educate health professionals in the future about the experience of older adults seeking health information online.

Ethical Issues

The Bournemouth University ethical approval (Appendix B) within stage one was also used to cover stage two of the study. As a part of this, health and safety approval was sought for stage two interviews to be conducted during working hours in private rooms on the university campus with adequate fire and buildings insurance. Approval was also given to pay travel costs for participants travelling to and from the university. Although two participants were happy to travel to the university for interviews, there were unforeseen issues with some participants travelling. Two further participants had functional issues that prevented them travelling comfortably, and a further two lived approximately 30 miles away from the university and were unwilling to travel this distance by public transport. Because it would cause significant problems for these participants to commute to suit my requirements, additional ethical approval was sought and agreed through the university for me to conduct the interviews within private rooms before or after support group meetings took place or, where this was not possible, within the participants' homes (Appendix F). In order to maintain levels of health and safety, I was chaperoned to interviews by a trusted friend who was aware of expected finish times and waited for me in the car outside. All interviews were conducted in rooms with phones and easy access to the doors. Participants who were required to travel to interview locations were asked about their arrangements in order to ensure that they were adequate and safe, and were offered expenses for their journeys.

As previously noted, participants were briefed prior to the interview in order to ensure that they were aware of the nature of the research and their right to withdraw. They were also issued with an informed consent form relating to the study and the use of recording equipment (Appendix I). As it was envisioned that discussing the history of a chronic illness may lead to distress for some participants, during the briefing process individuals were asked about factors that might lead to this risk of harm so as to minimise the risk of emotional stress. In addition, consideration was paid to

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providing participants with advice prior to data collection. Although the situation did not arise within this study, as a researcher I was aware of additional support and referral routes for participants. If I had been faced with a participant enquiry of this nature, I would have been prepared to refer the individual to a relevant healthcare professional who would be better suited to meeting their information needs. Participants were also debriefed fully in order to reduce misconceptions and discomfort, and to deal with the need for additional assistance or referral.

For ethical reasons, all participant information, transcripts, recordings, and so on were stored within a locked filing cabinet either at my home or at the university. All electronically stored information was password protected on the university computer system, and my personal computer and participant names were changed to pseudonyms throughout the presentation of results to maintain anonymity. After the study has been completed and the final thesis submitted, all confidential information relating to stage two participants and the interview transcripts/tapes will be safely destroyed.

Finally, participants were provided with the email and work postal addresses for my PhD supervisors within the School of Health and Social Care at Bournemouth University in case they wished to give feedback on my performance as a researcher or complain about any aspect of the research.

As well as health and safety and ethical considerations, additional thought needed to be given to ensuring that stage two data collection was conducted in a rigorous way and met standards of validity and trustworthiness.

Sampling

Once the statement of objectives had been outlined for stage two, purposeful sampling of participants was conducted in order to select informants who could provide descriptions of experience that would help satisfy the study's objectives around older adults seeking health information online. The inclusion criteria for participants was that they were over 60 years old, had been diagnosed by a registered GP as having a chronic condition, had not been involved with stage one of the study, and had personal experiences that they could recollect of seeking information relating to their

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health online. Seeking a parallel sample and not including stage one participants allowed for evaluations to be made in discussions and limited the risk of individuals having preconceptions about the study. Originally, it was considered that adults over the age of 65 would be recruited but further analysis of stage one findings showed little difference in the internet seeking behaviours of 60–65-year-olds and those aged over 65 years. It was perceived that those aged over 60 years would offer a unique perspective on the OHI-seeking experience.

A letter was written to the support group contacts gained throughout the stage one data collection process asking if it would be possible for me to speak at a group meeting to discuss the second stage of my study and to ask for volunteers (Appendix G). From this communication, six meetings were booked at support groups for people with multiple sclerosis (MS), stroke patients, people with osteoporosis, and those who had been diagnosed with haematological cancers, and two support groups for diabetics. During these meetings, I addressed the support groups and provided a description of stage two and the criteria for inclusion, and issued them with an information sheet (Appendix H) and requested their personal and contact details if they would like to be considered as a participant. These meetings resulted in obtaining the contact details of seven potential participants who wished to be involved with stage two of the study. One of these participants failed to meet the inclusion criteria for the study because he was unable to remember an experience of looking for health information online. He was therefore not included within the final sample. Phone calls were made to the six remaining participants to arrange suitable times for interviews. In line with phenomenological research designs, it was considered that the final sample size of six participants would give adequate opportunity to study the experiences outlined by the research design, and would yield interesting insights into the commonalities and variations between how these phenomena were lived within a variety of circumstances. Todres and Galvin (2005) explain that if the aim of a study is to obtain phenomenological depth, even “Single-case studies can yield findings that are attuned to focusing on very specific and highly textured details within their unique context” p. 2. Using this rationale, it could be argued that to pursue phenomenological breadth, a sample size of 6 is more than adequate.

Developing Rigour

Within their influential work *Naturalistic Inquiry* (1985), Lincoln and Guba outlined criteria for determining reliability and validity in the form of the parallel concept of ‘trustworthiness’. They defined trustworthiness as the quality of investigation or findings that made it noteworthy to audiences, and developed four criteria as naturalist enquirers equivalent to the traditional criteria for validity. These are as outlined below.

Credibility

This can be seen as parallel to traditional measures of internal validity and explores the issue of the inquirer providing assertions of the fit between respondents’ views of their life ways and the inquirer’s representation of the same (Schwandt, 2007). One way in which credibility was achieved within this research project was by prolonged engagement with the phenomenon under investigation. This involved spending enough time to become orientated in the situation and build trust with the individuals involved (Lincoln and Guba, 1985). To a certain extent, stage one also aided credibility by orientating the phenomenon (Van Manen, 1990) in order to ascertain a credible focus for stage two of the study.

Another method that was utilised within this research project to ensure credibility was peer debriefing. Lincoln and Guba describe this as a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session. It involves discussing the research at intervals throughout with a peer who is not in an authority relationship with the inquirer (in this case someone other than the PhD supervisors). This process allowed me to become exposed to searching questions and to test the working hypotheses, and provided an opportunity for catharsis (Lincoln and Guba, 1985).

Transferability

Transferability can be seen as parallel to external validity and deals with issues of generalisation in terms of case-to-case transfer (Schwandt, 2007). Transferability can be enhanced in this study by doing a thorough job of describing the naturalistic research context and the assumptions that were central to the research, and by making the impetus of the study explicit. This was achieved through careful consideration and a clear statement outlining the context and assumptions of the research. In future

research, it is the responsibility of the individuals who wish to 'transfer' the results to a different context to make a judgement about how sensible the transfer is.

Dependability

Parallel to reliability, dependability ensures that the process is logical, traceable and well-documented. This study adopted a technique for achieving dependability proposed by Guba; referred to as the inquiry audit (Lincoln and Guba, 1985). This involved working with a designated 'auditor' who was experienced in using similar research methods. The job of the auditor included examining research project documentation such as interview notes in order to determine acceptability and attest to dependability of inquiry. The job of the inquiry auditor also involved examining the final product in terms of data, findings, interpretation and future recommendations in order to confirm that these were accurately supported by the data. This latter process could also be said to assist in establishing the confirmability of the inquiry.

Confirmability

Confirmability is described as being parallel to objectivity within the study; it establishes the fact that the data and interpretations of an inquiry are not merely figments of the inquirer's imagination (Schwandt, 2007). As mentioned above, confirmability can be established by providing evidence of an adequate trail to enable the auditor to determine if the conclusions, interpretations and recommendations can be traced to their sources and whether they are supported by the inquiry. Lincoln and Guba (1985) noted that (Halpern, 1983) suggested six classes of raw record data to be reviewed:

- Raw data in the form of recorded videotapes, written field notes, documents and survey results.
- Data reduction and analysis products such as write-ups of field notes, summaries and condensed notes, theoretical notes such as working hypotheses and concepts.
- Data reconstruction and synthesis products; for example, themes that were developed, findings and conclusions.
- Process notes such as methodological notes, trustworthiness notes and audit trail notes.

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- Material relating to intentions and dispositions, inquiry proposal, personal notes and expectations.
- Instrument development information; for example, pilots, forms and preliminary schedules, observation formats and surveys.

By keeping an accurate record of this information throughout the research process, an audit trail was developed that enabled the auditor to determine whether or not the study's findings were supported and therefore assert confirmability within the study.

Research Procedure

Developing the interview structure

As previously noted, the first stage of any phenomenological study is to obtain rich life-world descriptions from participants. These descriptions can be collected in numerous ways, including through written texts describing an individual's experience, journals entries, autobiographies and, most commonly, through in-depth interviews. Whichever data collection technique is utilised, it is imperative that the participants can provide rich descriptions of their personal experiences, as opposed to speaking or writing generally about the topic. This study aimed to obtain rich life-world descriptions using phenomenological in-depth interviews in order to focus the data collection appropriately around the experiences of older adults seeking health information online, and to effectively handle the complexity of this lived phenomenon. The level of structure within a phenomenological interview ranges from unstructured (whilst still remaining focused) to semi-structured, where the interviewer has a small number of preconceived experience-based questions to help focus the interview. Within this study, a semi-structured approach to data collection was adopted in order to focus the interview on the phenomenological foci whilst avoiding limitations being placed on the participants' ability to provide a flowing narrative account of their individual experiences. Conducting quality, unstructured phenomenological interviews can be extremely challenging and is best left to very experienced researchers because there is more potential to make methodological errors when operating in this manner.

The interview structure that was developed began with a request for the participant to describe as fully as possible a relevant experience of seeking OHI as an older adult.

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After the participants provided this, they were asked to describe six further, more specific types of OHI-seeking/sharing experiences in turn. These specific experiences were taken from previous literature and stage one results, and allowed me to incorporate some aspects of the possible stage two foci that were not selected to be the main focus of stage two. The final interview structure was as follows:

- Can you please describe an experience where you looked for health information online?
- Can you please describe an experience where you were unable to find health information online?
- Can you please describe an experience where you found poor quality health information online?
- Can you please describe an experience where online health information helped you understand something better?
- Can you please describe an experience where online health information made you feel confident?
- Can you please describe an experience of sharing online health information with a health professional?
- Can you please describe an experience of sharing online health information with friends, family or support group peers?

The barriers to OHI seeking were not explored to the same extent as in stage one because the aim of stage two was to gain a more focussed breadth of information regarding the nature of the OHI seeking experience for older adults with chronic health conditions. However participants were asked to describe experiences of being unable to find OHI, and locating poor quality OHI.

Pilot study

Prior to stage two data collection, a pilot interview was conducted in order to test the interview structure and equipment, and to gather feedback on the briefing and debriefing processes as well as my coherence as an interviewer. This interview was conducted on a family member who was living with a chronic health condition. The feedback from the pilot interview suggested that it might be worthwhile including a discussion of what is expected of the participant within the briefing process in order

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to reiterate that the process requires descriptions of specific experiences, as opposed to general discussion on the subject area. The briefing process was then altered to include this explanation so as to maximise the opportunity to obtain rich life-world descriptions.

Stage two interviews

Stage two interviews were arranged to be conducted either on campus in private rooms during office hours, within private rooms within the support group venue/day centre or in participants' homes. One interview was scheduled for each participant. The duration of the interview was not specifically limited but, taking the pilot interview into consideration, was foreseen as lasting approximately one hour (which all interviews did approximately). Immediately prior to the interviews taking place, the participants were provided with an information sheet outlining the study (Appendix H) and were asked to complete an informed consent form including specific consent for the interview to be recorded (Appendix I). Participants were also given a brief explanation of what was going to happen within the interview, and were reassured that their participation was voluntary and that they had the right to withdraw from the interview without providing an explanation at any point. Each interview was recorded using a Sony ICD-B500 handheld voice recorder in order to collect comprehensive experience-based data that could be transcribed at a later date. After the life-world experiences had been collected, participants were asked if they would like to receive a summary of the key findings from the study once the thesis had been submitted, and were provided once again with my contact details in case they had any further questions regarding the research. The transcription was conducted using the interview recordings, which were later inputted completely into Microsoft Word. This was extremely challenging because it took much longer than was initially expected. Once the initial transcription had been taken, it was checked twice using the recording in order to eliminate possible errors and improve rigour.

Applying Giorgi's descriptive phenomenological method

As previously stated within this chapter, Giorgi (2009) provides a discussion of the systematic steps involved in conducting his descriptive phenomenological method in psychology (Giorgi, 1985, Giorgi and Giorgi, 2004, Giorgi, 2009). The following will

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provide an elaboration of each of these steps, alongside of a discussion of how each was conducted within the current research project.

- Reading the transcriptions thoughtfully in order to get a narrative sense of the text as a whole piece.

The first stage of Giorgi's method was conducted once the interview data had been fully transcribed and checked. It involved reading carefully and thoughtfully through the transcribed interview data a number of times until a stage was reached where I was able to gather a sense of the whole. Giorgi states that, in order for this stage of the analysis to occur, one must assume the attitude of the scientific phenomenological reduction by bracketing past knowledge and being sensitive to the implications of the data for the phenomenon being researched (Giorgi, 2009). As previously stated, this involves reducing things that are intentionally related to consciousness, and focusing on the role of subjectivity (Giorgi, 2009). This was achieved by focussing on the meaning as opposed to the descriptions provided.

I found that during this stage I felt a desire to enter straight into the analysis and to try and clarify a sense and make explicit what was happening. Because the purpose of this stage is to merely operate with a general sense of what the transcription outlines, a certain amount of control had to be exercised to prevent over analysis at this stage. Once an overall sense had been observed without making observations explicit, I was able to continue to the next step of the analysis procedure.

- Dividing the descriptions up into units signifying changes in meaning – 'meaning units'.

Since the interview transcripts for phenomenological research are often extremely lengthy, Giorgi (2009) suggests breaking them down into more manageable parts in order to do them justice. This was indeed the case with the current study where I was faced with six hours of transcribed experiential data that needed to be analysed..

Giorgi (2009) states that as a contrast the researcher may decide to break that data down using structure such as paragraphs or sentences. However, using this approach means the information is broken down structurally or grammatically as opposed to using an approach that is psychologically sensitive.

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In order to break down the experiential data that I had collected into units of meaning, I once again re-read the experiences whilst assuming the phenomenological scientific reduction. Whilst re-reading, I started to make a mark in the margins of the paper when there was a change in the meaning within the text. I found this process to be one that could be conducted using intuition and it did not require a high level of cognitive processing. It felt almost natural and automatic to divide the data up in this way because it was very clear to me when there was a significant shift in the text's meaning. Giorgi (2009) explains that the way the text is broken up into meaning units correlates with the specific attitude of each researcher, and it is acceptable for different researchers to develop unique structures of meaning units because meaning transitions can genuinely occur in different places. He suggests that the most important part of the process with regards to meaning units relates to how they are transformed.

- Expressing the sense of each meaning in a general manner.

The following stage relates to the transformation of the meaning units into psychologically sensitive expressions (Appendix J). According to Giorgi, the justification behind this approach is based upon the fact that the existing meaning units reflect a description of the experienced phenomenon as they presented themselves to the consciousness of the researcher within their own natural attitude, therefore inviting a re-examination of the findings by the critical other in order to give the description added strength (Giorgi, 2009). During this stage of the method, the researcher returns to the beginning of the description, which is now divided into units of meaning, and then considers each meaning unit individually. The researcher's aim is to develop a method of conveying the unit of meaning as expressed in the participant's natural attitude in a more suitable way that will uncover the psychological implications of the life-world description (Giorgi, 2009). During this process of transformation, Giorgi (2009) also suggests that the generalisation of the data may occur to a certain degree in order to make it easier to integrate the data from various participants into a single structure.

This stage of the analysis process was extremely time consuming and involved long periods of reflection and re-reflection. My ability to perform this stage of the analysis was helped by attending a two-day phenomenological workshop led by Amedeo

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Giorgi where he demonstrated how to conduct this stage of the descriptive phenomenological process. Although this gave me increased confidence in my ability to perform this phase of the analysis, I still felt additional research was needed in order to accurately transform the data. I therefore referred to a number of examples from Giorgi's own work relating to how the stage should be performed in order to develop my overall understanding (Giorgi, 2009). After writing several versions of the transformation and gaining feedback from an experienced phenomenologist regarding the process and final result, I felt happy to move on to the next step of the research process.

The discussion of the final two steps of the analysis process will be discussed concurrently to reflect the integrated nature of the two phases.

- Developing a 'structure' that integrates the common meanings throughout all life-world descriptions;
- Opening out the structure and elaborating on the common themes from within by using original participant data to develop the richness of the analysis.

The development of the experience structure involves the researcher using a process of imaginative variation in order to determine the most invariant elements of the experience (Giorgi, 2009). Imaginative variation is an exercise whereby the researcher makes intentional alterations to the experience via their imagination by either extracting or adding aspects of the experience (Spiegelberg and Schuhmann, 1982). This process allows the researcher to discover the aspects and/or qualities that make a phenomenon uniquely what it is and without which would be something else (Van Manen, 1990). This experimentation then leaves the researcher with the 'essence' or 'bare bones' of what constitutes the phenomena articulated as the structure (Holloway and Todres, 2003). It describes the common themes or essential parts from within the experience that identify the phenomenon and transcend the experiences of different individuals. For example, within the context of this study, the structure helps answer 'what are the invariant themes that emerge in all experiences of older adults looking for health information online?' and 'What essential features do all these experiences share?'. Giorgi (2009) describes the structure of experience as a

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way of comprehending the unity of concrete data and of understanding why the diverse facts and concrete details can belong to the same phenomenon.

The effective presentation of phenomenological data not only provides the structure of experience, but also communicates the texture through the articulation of constituents. Constituents in this case have been presented after each structure, and can be described as interrelated elements or units of the structure of experience that are mindful of their roles within the whole (Gurwitsch, 1964). They express the individual invariant themes from within the structure of the experience and allow for elaboration and rich description, including direct quotations from participant interviews that provide additional texture to the analysis. Effectively, the articulation of constituents allows the researcher to take the bare bones or structure of an experience and open them out in a way that will develop a rich description of structural components and help provide examples of how the invariant aspects of experience were specifically lived by those involved. This breakdown of the structural elements of the description also allows for the presentation of subtle variations between the structural elements of the experience, thereby communicating what makes each of these experiences unique to the individual.

The process of articulating the structures and constituents of an experience is far from a straightforward linear exercise. Todres (2005) states that, in order to effectively synthesize the typical themes from the descriptions within the life-world and develop the elements of an experience, the researcher must retain a sense of the whole experience, as well as being aware of the transformed data contained within the individual constituents or insights (Todres, 2005). In other words, prior to the articulation of the structure of experience and constituents of that structure, the researcher has to enter into a process of moving between the transformed data, invariant themes (structure) and the textual constituents. This process helps ensure that the elements of the structure are mindful and built in relation to their roles within the whole (Gurwitsch, 1964), while the whole is constructed in a way that is dependent on the individual parts. Therefore, the transformation, structure and constituents are deeply interrelated and reliant on each other to provide a holistic presentation of the experience.

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I personally found this task extremely challenging whilst undertaking the research process. Although experienced phenomenologists may enter into this reflexive thought process automatically, steps had to be taken to help me focus my analysis in this way. In order to achieve this backwards and forwards movement, an initial structure and constituents were written; the constituents were then used to rewrite the structure. This process of writing and re-writing each element based on the last was prolonged, along with continual reading and reflection of the original phenomenological data in order to continually refine the analysis and develop a continuous relationship between the parts and the whole of the experience. Exercises like this allow researchers to make better sense of the parts and to see whether the emerging formulation requires additional refinement in order to better account for some part (Todres, 2005). As this process continued, I could see my analysis developing into a far richer description, and I witnessed the emergence of insights that were lost in the original draft of structure and constituents. I found this exercise extremely rewarding and worthwhile in developing a rigorous phenomenological analysis and effective presentation of the findings. In addition, this approach allowed me as the researcher to capture the complexity and ambiguity of the lived world being described by participants (Finlay, 2008). As well as this challenging aspect to the analysis process, additional functional obstacles were also encountered when balancing both the rigour and accessibility of the presentation of my data, or the scientific and communicative concerns. The specific nature of these concerns will now be discussed in greater depth, alongside the challenges that I encountered in balancing these considerations within the final analysis.

Chapter 8. Stage Two Results

Introduction

The aims of the following chapter are, first, to provide a justification and explanation for the analysis and presentation of stage two phenomenological data and, second, to present the results in a way that can effectively communicate the key elements of the experiences in line with phenomenological tradition. Also discussed will be the challenges that were faced in presenting phenomenological data in a way that is both rigorous and accessible to a general audience.

Presentation of Stage Two Data

As previously noted, semi-structured interviews were conducted in order to focus the interview around the phenomenological foci, whilst avoiding limitations being placed on the participants' abilities to provide flowing narrative accounts of individual experiences. The interview structure contained one opening grand-tour question regarding general experience and six more focused experiential questions (see stage two methods). The first four focused experiential questions dealt with online health information (OHI) seeking, whilst the last two could be classed as OHI-sharing experiences. Analysis begins with a discussion about the overall experience of OHI seeking, followed by the presentation of analysis for the six more specific types of experience that participants were asked to describe (focused experiential questions). The analysis concludes with the presentation of a summary of key findings from within the phenomenological data.

The analysis for each experience begins with the articulation of a unique structure, followed by textural constituents as per the phenomenological tradition and Giorgi's descriptive phenomenological method. This chapter provides a structure for the general and six more specific experiences, followed by the constituents for each, in order to effectively communicate the invariant elements and individual texture of each experience. Although the data has been presented in this way in line with Giorgi's descriptive phenomenological method (Giorgi, 1985, Giorgi, 2009), it is important to consider the reflexive process that was entered into in order to conduct a true phenomenological study resulting in both structure and constituents (see stage two methods chapter).

Balancing Scientific and Communicative Concerns

By adopting the process of moving back and forth between the emerging formulation of the holistic structure of experience and the individual parts, a level of refinement occurs that helps maintain methodological rigour. This rigorous formulation addresses the scientific concern of the study by achieving a level of descriptive adequacy (Ashworth, 2000) that allows the researcher to arrive at a linguistic synthesis that may account for the individual units of meaning (Todres, 2005). In other words, rigour is established by adopting a reflexive approach to data analysis that ensures additional refinement and provides sufficient evidence of the description of the life-world. The reader is effectively placed in the position of the researcher and is provided with the evidence from the data in order to be able to identify which elements of the experience led the researcher to develop their conclusions. This process involves an element of simplification so that the results can be shared while ensuring the transparency of the exercise. Put simply, using the analogy of a mathematical problem, a mathematician would show their working in order to address the scientific concern, thus showing readers how they arrived at their conclusion and allowing them to see inside the work.

While it is essential that phenomenological studies address the scientific concern, it is not the only consideration to make in terms of achieving a quality analysis. Researchers must also address concerns around the accessibility of the data to others, or the communicative concern. The communicative concern is to find ways of expressing the analysis so that it facilitates understanding for potential readers (Todres, 2005). While the researcher has engaged in a long process in order to develop an analysis that is understandable and meaningful to them, additional consideration needs to be paid to ensure that full comprehension of the analysis is accessible to others outside their stream of consciousness. Halling (2002) comments that, although phenomenological research may be challenging and exciting for the researcher, this excitement often fails to come out when communicating the published account, especially for those who are unfamiliar with phenomenological philosophy. He explains that phenomenological research is valuable and even essential; therefore, it is part of our task and our responsibility as researchers to make this research readily available to those who might find it helpful or of interest (Halling, 2002). Because it is the intention to make this study accessible to a wide audience in order to make

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maximum impact, during this research project I spent a significant amount of time considering how to address the communicative concern.

As previously stated, balancing the study's scientific and communicative concerns became an ongoing challenge during this research project. Initial attempts to present the analysis paid great attention to ensuring the rigour of the study, to the detriment of the accessibility of the study for others. This led me to try a number of exercises in order to improve accessibility; primarily free writing and discussion, and feedback from others. Free writing or discussion (recorded on tape) allowed me to step out of the role of researcher and provide an explanation of the findings, as I would discuss with others, as opposed to how I had previously been taught to write in a standard research report. I found that this gave me the ability to free myself from previous bad habits that were inhibiting effective communication. In addition to these exercises, I sought feedback from trusted friends and family who did not have a background in phenomenological philosophy in order to ensure that my work was presented in a way that did not alienate them as a potential audience. It also involved me being more reflective about the process and challenges that I underwent while developing the analysis, and forced me to be more transparent with the reader and engage them in the process. This also involved me paying serious attention to the manner in which the data was presented so as to enable the readers to see the wood from the trees in terms of the key findings that came from the study. On reflection, it was decided that the explanation of the rationale behind the presentation, as well as the inclusion of a summarisation of key themes, would help make explicit the crucial information that must be taken away from the study.

Prior to the presentation of the structure and constituents of the overarching experience, it is necessary to explain that not all participants provided a valid description for each experience. This was sometimes due to them not being able to recall a specific experience of each type, or them just speaking far too generally for it to be classed as description of a specific experience. Appendix K shows a chart outlining who provided the descriptions for each of the experiences. I will now provide the analysis for the overarching experience.

The Overarching Experience: The Experience of Looking for Health Information Online

Initially I had intended to present the structure and constituents for the general experience of looking for OHI as a separate experience. However, after the analysis had taken place, it became clear that the structure and two constituents for the overarching experience also applied to all the more specific OHI-seeking experiences (experiences i–iv). Therefore it was decided that it would be appropriate to provide an analysis of the common structure and two common constituents for all seeking experiences together in order to avoid repetition throughout the analysis of the more specific seeking experiences. Prior to this decision being made, the two constituents identified within the general experience had been described in detail within the analysis of information-seeking experiences i–iv, which was viewed as lengthy, repetitive and detrimental to ensuring the communicative concerns of the analysis were sufficiently met. Therefore, the structure and constituents described below apply to different types of experiences under the umbrella heading of OHI seeking. The sharing experiences (v and vi) are lived as a result of seeking experiences; therefore, although it is implied that the constituents have occurred prior to the sharing experiences taking place, it is not explicitly stated.

Structure

The experience of OHI seeking occurs in response to the identification of a gap in healthcare knowledge. This can relate either to personal knowledge or to the knowledge of an individual within their social circle. The experiencer perceives this health information deficit as negative and therefore wishes to relieve themselves/another of it by becoming more informed. The individual describing the experience feels that this is, to a certain extent, their responsibility to ensure that they become more informed. There emerges a desire to seek information about their health and demonstrate ownership of their bodies and/or the bodies of those they feel responsible for.

I will now elaborate on the central constituents of the experience of general OHI seeking.

Constituents

- i. Identifying an information requirement
- ii. Taking responsibility

- i. Identifying an information requirement

The first central constituent for all of the OHI-seeking experiences was identifying a health information requirement. The specific nature of the information requirement varied between participants. Some participants noted that the health information deficit took the form of a need for general information about a recently diagnosed chronic condition:

“So when I was first diagnosed with osteoporosis I thought where do you go? What do you do? So apart from Rachel the osteoporosis nurse, who my doctor referred me to, getting all my information off her, and then snippets that she dropped and mentioned at our talk, I thought right, I’ll go on the internet and see if anything is umm available.” **(Denise)**

Edward also describes an experience of looking for general health information relating to a recently diagnosed chronic condition:

“After I was diagnosed with thrombocytopenia I looked that up on the net because the explanation given by the consultant uhh, was uhh, very simplified probably, thinking basic, and I wanted to find out a little more about it.”
(Edward)

Other participants identified more specific information requirements in terms of their ongoing chronic illness. Brian describes a time that he looked up a form of cancer therapy on the internet because he wanted to know a bit more about it, whilst Denise discusses looking up a form of medication:

“The drug that I take, can I mention it? Yeah, yeah Fozimax I wanted to know more information about that and how it works.” **(Denise)**

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Whilst the majority of participants discussed a personal information deficit, a number described experiences where an individual that they felt responsible for had an information need, and they took the responsibility and initiative to fill it. Although this was apparent to a lesser degree within OHI-seeking experiences, it was most prevalent during the experience of sharing OHI with family/friends or peers at the support group (referred to from now on as ‘others’).

Participants implied that having a health information deficit was perceived by them as negative by describing that they attempted to rectify the situation. Claire explained that she felt dissatisfied with the lack of information, whilst Denise described feeling worried when she had an information deficit regarding a drug that she was taking:

“...you’re very worried about, you know, you’re thinking this drug is going into my body and what’s it going to do?” **(Denise)**

This constituent demonstrates that the motivation for seeking OHI was to relieve an information deficit. This was either related to the individual’s personal health or to the health of a person they feel a level of responsibility for. Individuals turned to the internet in order to become more informed regarding their specific healthcare needs. By taking the steps to relieve the information deficit, participants ultimately demonstrated taking responsibility for ensuring that either they, or an individual within their social circle, were fully informed about their health care.

The aforementioned tells us that, although the experience of identifying a gap in health information is a negative experience, it is essentially experienced in different ways within the above descriptions. For example, Claire explains feeling dissatisfied by her lack of information, whilst Denise describes feelings of worry and concern for her wellbeing.

I will now move on to describe the next central constituent that has been identified within the experience of older adults seeking OHI.

ii. Taking responsibility

The next unifying characteristic of the general and more specific experiences was that all participants described taking responsibility for either their own health or the health of another person for whom they felt responsible. The majority of individuals demonstrated a desire to take control of their own health and wellbeing, and displayed a sense of routine ownership over their own health. Participants did not specifically justify this experience but instead described it as part of a natural process, as if it was something they did without conscious awareness. In some cases, participants described taking initial and complete responsibility for becoming more informed about their health care. Fiona provided an example of this whilst describing a time where she found poor quality health information online:

“Well, I’d actually, I actually looked up diabetic neuropathy umm because everybody talks about it, and I’d, I’d started to have problems...I started to get umm pins and needles in my calf and I thought what’s happening? Do you know what I mean? And I looked it up to find out what diabetic neuropathy was.” **(Fiona)**

Fiona demonstrated here the assumption of responsibility for becoming more informed about an aspect relating to the management and care of her own chronic condition. She used her previous knowledge regarding her condition and was guided by this to search for the relevant information as opposed to turning to another individual. This experience demonstrates a high level of perceived responsibility. More frequently, participants described experiences that implied a level of shared responsibility for their health and wellbeing:

“Nobody was interested, and I don’t mean, we have a wonderful practice and very good doctors [pause], but these days I’m afraid if you don’t fit into a box that you can easily tick, you fall between those boxes, then be wary because they don’t want to get involved because they think its going to cost a lot of money or it’s going to take a lot of time, so I found out as much as I could myself about the Lichen Planus.” **(Claire)**

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Claire demonstrated here that she perceives that both her and her health professionals have a level of responsibility for ensuring that she is adequately informed about her health, and both have responsibilities in terms of management. She also shows that she feels that, because health professionals had been unable to fulfil their responsibility, it had then shifted towards her to ensure that she had the information she requires to effectively manage her condition. Brian also provided an example of a similar experience whilst discussing a time when OHI increased his confidence. Here he felt the need to take responsibility for becoming informed about an aspect of his health care because the information was not provided by the health professional:

“...with the prostate you only saw the person once and then, so you had to make your own mind up then, and that’s why I went on the internet. Because although they gave you a book of what prostate cancer is, and the kind of treatments that you can have, what will happen if you have the prostate removed, or what will happen if you have radiotherapy, or you know the side-effects you would have, and how long you have got to go to have the treatment for, there was no-one to speak to a bit about Brachytherapy, where there was no-one actually to speak to about it so you know, for what I wanted to know I had to go onto the internet about.” **(Brian)**

Brian and Claire’s experiences both demonstrate that they felt personally responsible for filling the gaps in their healthcare knowledge left from interactions with healthcare professionals. They therefore both acknowledged the role of patient and practitioner in working together to ensure that the patient is fully informed.

Whilst discussing an experience of not being able to find OHI, Denise described a situation where she felt that she had to research a medication that was prescribed by a health professional further before taking it, thus demonstrating a perceived responsibility for ensuring that she was fully informed as opposed to relying entirely on the knowledge of professionals:

“I’m the kind of person who, if I have been asked to take a drug, I like to know the whole background of the drug. I just can’t take a drug for the sake of taking. I’ve got to know what this is doing to my body.” **(Denise)**

This statement specifically demonstrates this participant having a sense of ownership and control over her own body and the right to control what goes into it. Edward described taking responsibility in order to be able to judge how knowledgeable health professionals were so as to effectively manage the situation:

“It enabled me to question anything the umm, doctors and nurses were telling me about it, so I’ve been able to listen, to see, or to make a judgement to how well they were knowledgeable on the subject, so that’s all really.” **(Edward)**

These statements are interesting because they not only demonstrate Denise and Edward’s intention to take responsibility for their healthcare information needs by adopting a partnership approach, they also show a desire to confirm information provided by health professionals. This shows a large amount of confidence in their abilities as OHI seekers and a potential shift in the information power balance associated with the traditionally paternalistic patient–practitioner relationship.

While participants also described a process of taking responsibility for their health care within the specific experience of ‘OHI helping individuals understand something better’, interestingly their experiences routinely occurred after contact with a health professional where the person in question felt the need for additional information. Therefore, in this situation, the participant felt the need for additional information other than that provided by the health professional in order to understand an aspect of their condition. For example Brian explained that, although his health professional provided him with an information booklet outlining possible treatment options for his chronic condition, he felt the need to find more information in order to make an informed decision.

Denise and Fiona both described how their information need was created after being prescribed a drug by their health professional and feeling that they needed more information on it. This shows that, although participants were willing to work with their health professionals in order to manage their chronic conditions, they also intended to take an active role in their self-care and in regaining some control over their own bodies.

Throughout all the above examples, individuals demonstrated a perceived personal responsibility for their health and for ensuring that they were fully informed about different aspects of their health care. However, most participants also referred to the fact that they perceived the responsibility to be one that is shared with their health professionals. This demonstrated an expectation and an intention to work in partnership with health professionals in order to become more informed. In some cases, participants showed this by ensuring that they were fully informed prior to a healthcare interaction, whilst others used OHI to confirm or expand on information provided by their healthcare professional. Some described deciding to take responsibility because they perceived the health professional to be unable to fulfil their role of responsibility. However they occurred, these experiences demonstrate a willingness to work in partnership with the health professional in order to ensure positive health outcomes. They also demonstrate a shift in the traditional paternalistic relationship between healthcare professional and patient. The traditional relationship would see the assumption of full responsibility for providing healthcare information lying with the professional, who provides advice that is taken and not questioned by the patient due to the nature of the hegemonic relationship and unequal power balance. The experiences described above show an automatic assumption of the more recently discussed partnership approach, which understands the roles of both patient and practitioner in ensuring the patient is fully informed.

It is important to consider that, in the case of the experience of sharing OHI with family/friends or peers at the support group, taking responsibility for their own health was demonstrated to a much lesser degree than in the other experiences. Because it describes a 'sharing' as opposed to a 'seeking' experience, it instead demonstrates participants feeling a level of responsibility towards another individual's health. This is also shown within examples for other experiences to a minor extent.

During the experience of sharing with others, individuals identified that someone within their social circle, as opposed to themselves, had the specific health information need. These people assumed partial responsibility for ensuring that those around them in their social circle were provided with the information that they required regarding their health. Participants described sharing the trusted and relevant

OHI that they had located with other members of support groups and with friends and family in an attempt to assist them in becoming more informed by benefiting from the information. This will be discussed in more depth as the constituent labelled ‘social responsibility’ for this specific experience.

This idea of responsibility for others was also present within OHI-seeking experiences. Whilst describing an experience of finding poor quality health information, Fiona discusses a time in which she was looking for OHI to fulfil an information deficit that she had in order to help manage her daughter’s condition:

“I can remember one occasion when I looked up umm, medication that was not for diabetes. I was actually looking up medication that I’d been prescribed for my daughter for depression.” **(Fiona)**

This statement is extremely revealing because Fiona states that *she* had been prescribed the medication for her dependent daughter, thus demonstrating further the assumption of responsibility over her daughter’s health. In addition, whilst describing experiences of sharing OHI with a health professional, both Fiona and Denise recall times when they researched possible medication options for someone with the same chronic health condition as themselves and contacted their health professional to discuss the information that they had located. Fiona also described an additional experience of OHI seeking where she went online in order to find information to help inform others with the same chronic condition as her. Fiona did this so that she could set up her own support group and share knowledge with others.

These experiences demonstrated that, in addition to participants taking responsibility for their own health, some also felt partially responsible in helping others self-manage their conditions. In some cases, participants made explicit that this was due to a perceived superior status as an online information seeker and a need to provide information to those without access. This behaviour suggests that, for some individuals, the flow of health information has developed from a unidirectional one (traditional paternalism) to a multidirectional partnership model, and that a network has been developed where health information is passed between lay individuals. These people assumed partial responsibility for ensuring that those around them in

their social circle were provided with the information that they required regarding health. Participants described sharing the trusted and relevant OHI that they had located with other members of support groups, friends and family in an attempt to assist them in becoming more informed.

In summary, a central constituent throughout all the experiences was one of taking responsibility. Whilst some participants discussed their responsibility towards their health care independently, others discussed it alongside the perceived responsibility of health professionals. Some individuals felt responsibility for informing others within their social circle, such as dependents and peers at the support group. It could be concluded that responsibility for health information has shifted from a unidirectional paternalistic hegemony to a multidirectional partnership model, whereby responsibility is assumed by patient, practitioner and peers in order to achieve positive health outcomes.

I will now move on to discuss the subtle variations in how the constituents presented themselves within the more specific experiences.

Variations in Common Constituents

The preceding demonstrates that all OHI-seeking experiences involved the individual living the experience identifying a health information need and taking the responsibility to fulfil that need. However, it is important to note that, although these experiential similarities exist, the way that they were manifested within different experiences varied. Table 7 shows how the central constituents that applied to all seeking experiences varied between the different types of experience. It also provides details of how they subtly applied to the two sharing experiences.

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The Experience	Characteristics of the Information Requirement	Characteristics of Responsibility
Experience of not being able to find health information online	Personal health information requirement identified, relating to own chronic condition	Taking responsibility for own health; specifically, willingness to adopt a partnership approach to working with health professionals
Experience of finding poor quality health information online	Health information requirement identified, relating to either own chronic condition or someone else's chronic condition within the social circle	Taking responsibility for own health <i>or</i> the health of another. Willingness to adopt a partnership approach with health professionals and other individuals within the social circle
Experience of online health information helping participants understand something better	Health information requirement identified relating to either own chronic condition. The information requirement is different for this experience than for others. In the case of OHI helping an individual understand something better, the information requirement is exclusively identified after a consultation with a health professional. This is as a result of the health professional providing some information but the individual perceiving that they need further information on the same topic	Taking responsibility for own health; specifically, willingness to adopt a partnership approach to working with health professionals
Experience of online health information increasing participants' confidence	Personal health information requirement identified, relating to own chronic condition	Taking responsibility for own health; specifically, willingness to adopt a partnership approach to working with health professionals
Experience of sharing online health information with a health professional	<i>Not explicitly discussed within the sharing experience therefore not a central constituent. However, it is implied that it has already occurred because the sharing experience is lived in response to the individual having an initial seeking experience</i>	Participants imply that they have already taken responsibility for their health or the health of another, and provide evidence of a desire to work in partnership by sharing this with their health professional
Experience of sharing online health information with others		<i>Termed social responsibility and discussed as a separate constituent. Implied that they have already taken responsibility for their own health prior to the experience but describes much more the responsibility to others to ensure that they are fully informed. This therefore demonstrates the emergence of a social sharing network in which responsibility is shared</i>

Table 7. Variations between individual experiences.

The following will elaborate in greater detail on the analysis of the six specific experiences of searching for OHI, in order to articulate some important components of the overall experience and uncover the varying themes between different seeking and sharing experiences.

1. The Experience of Not Being Able to Find Health Information Online

Structure

This experience begins, as with all other internet seeking experiences, with a felt need and expectation in terms of information required to fulfil an identified deficit, and continues to be defined by the assumption of a level of personal responsibility to become informed. The expectation is that the information will be able to fulfil the information need adequately. However, after turning to the internet and locating some OHI, the individual feels that the information fails to meet their expectations. The failure to meet the expectations and therefore fulfil the information need causes negative emotions such as fear, apprehension, dissatisfaction and concern. What follows is a prolonged period in which the information need is left unmet and the deficit is maintained.

I will now elaborate on the unique central constituents of the experience of not being able to find health information online:

Constituents

- i. Identifying an information requirement*
- ii. Taking responsibility*
- iii. Unfulfilled expectations
- iv. Being left in the dark

Because the first two constituents (i. identifying an information requirement and ii. taking responsibility) have already been discussed as part of the wider experience, this discussion will begin with an elaboration of constituent iii.

iii. Unfulfilled expectations

Although participants were able to locate OHI relating to their queries, they also explained that they felt that what they had found failed to meet their specific information needs. In order for this experience to occur, the individual must have had a specific idea of what information they were looking for prior to information seeking. The fact that the individual already had expectations in terms of OHI also implied that they had confidence in their ability to discern the information required to effectively self-manage their condition, and had strong ideas of the information that

they required. Denise described how the information that she located failed to meet her information needs:

“Well, it was, just named the drug, and the components of the drug, and...but it didn't really tell me, you know what research has been done on the drug, that's, that's what I was hoping for...it didn't really give me any information, it didn't tell me what how it worked, what it did and umm so I just didn't find it efficient.” **(Denise)**

Denise was looking for research on the drug as opposed to a pure description, which shows that she felt she needed scientific evidence in order to provide her with the information and reassurance that she was seeking. This demonstrates that she had a perceived ability to discern OHI and values research more highly than other health information sites. This displays an example of participants entering into a process of discerning quality as opposed to accepting the first piece of relevant information available.

Fiona also described how the information that she found failed to meet her needs in terms of OHI:

“...there is nothing there that describes what is a hypo and what is a hyper, it talks about hypo and a hyper but it didn't actually tell you what might happen at that point in time...when I actually looked it up, it talked about people having a hypo and having low blood sugar, but it didn't talk about the effect that would be.” **(Fiona)**

This statement showed that Fiona had a specific idea about the information that she required to be able to manage the possible side-effects of her chronic condition (hypoglycaemia and hyperglycemia). She felt the need to become more informed about what might happen to her in order for her to be prepared for that situation. However, the information that she located failed to provide this relief. This again demonstrates that Fiona had the confidence in her ability to discern the exact information that she required.

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Participants showed high levels of self-assurance in their abilities to distinguish and recognise the information that they required to self-manage their conditions. This demonstrates high levels of confidence in their ability to take responsibility for their own health. Participants had a specific idea about the information that they required but found information that they felt was too descriptive and was not able to assist them in being fully informed. In other words, participants had unfulfilled expectations in terms of the OHI that they located.

This tells us essentially that unfulfilled expectations occur when individuals have strong preconceived ideas about the nature of the information and its ability to be utilised to improve their situation. In addition, the information that they found in reality failed to meet the same standard of the preconceived ideal, and was therefore unable to have the desired positive effect on their situation. The next constituent will move on from this and discuss what occurred after the expectations were left unmet.

iv. Being left in the dark

After locating information that was perceived not to meet their specific needs and expectations, participants experienced an extended period of time in which their requirements in terms of health information were left unmet. In other words, they were unable to locate the OHI that they required after initially finding something that did not meet with their expectations. They also failed to have their information deficit relieved by other sources. This meant that individuals were effectively ‘left in the dark’ and were not able to locate the information to help them self-manage their conditions for some time after the initial experience. Denise explained that she tried multiple times to locate the information that she required online and eventually turned to a health professional:

“So then I just dismissed it, and went back to the information...Ooh well I was just getting the same information. And then Rachel [osteoporosis nurse] couldn’t really fill me in with any more information on it because that’s all she had.” **(Denise)**

This statement demonstrates that, although Denise felt that it is primarily her responsibility to ensure that she is informed about aspects of her health care, she also

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designated a certain amount of responsibility to health professionals as an information source. This again is an example of Denise's expectation to work in partnership with her healthcare professional in order to manage her chronic condition. Fiona also described being 'left in the dark' for an extended period:

“And it was some years, and I didn't find it on the internet before you know, that I found out for example that somebody might act you know as if they're drunk because they are having a hyper, and that people might arrest them, and that the police have done, taken them away. I didn't know that and it took me a long time to find out because it wasn't specifically on the web.” **(Fiona)**

Fiona makes this point in a way that seems to assert her concern about how not knowing something could potentially have such serious implications and affect her ability to cope with her chronic condition. She also demonstrates her reliance on the internet as an information source, explaining that because the information was not online it took her a long time to find out. Fiona also goes into more detail about the negative implications of being 'left in the dark' and not being fully informed about a condition:

“...and that was really difficult, because you're left sitting there knowing that these things could happen, but not knowing what it actually means for you.”
(Fiona)

This account implies that the individuals may need to be informed in order to be confident and reassured about their health so as to effectively manage it in the future.

The discussion of the above constituent describes the experience of being left in the dark as 'not knowing' for an extended time and being left without desired reassurance in the form of information in order to effectively manage a chronic condition. Denise experienced being left in the dark by not receiving the information she required to give her reassurance about her chronic condition from the internet or any other source, whilst Fiona stated that for her it was experienced by knowing that there were side-effects for her condition but not knowing what this meant for her.

I will now move on to discuss yet another kind of experience in relation to online health information seeking.

2. The Experience of Finding Poor Quality Health Information Online

Structure

As with all OHI-seeking experiences, the experience of finding poor quality health information online begins with the individual identifying a health information need and continuing by taking responsibility to fulfil this need by looking for OHI. They have specific expectations of this information in terms of quality. During this particular experience, the individual is confronted with multiple pages of relevant information regarding their enquiry but it all fails to meet their specific expectations in terms of quality. Therefore, the individual already has criteria in mind of what constitutes quality information prior to this seeking activity. The individual has confidence in their ability to discern the quality of OHI but has concerns about others' abilities to do the same. Being able to effectively discern good quality OHI is seen very much as a potential issue for other people, and is not something that would affect them due to their perceived superior ability in being able to judge OHI quality.

I will now outline the central constituents that were identified for this specific OHI-seeking experience.

Constituents

- i. Identifying an information requirement*
- ii. Taking responsibility*
- iii. Unfulfilled quality expectations
- iv. Confidence and concern

As with the previous experience, the first two constituents have already been presented and so the central constituents that were unique to this specific type of OHI-seeking experience will now be discussed in greater detail:

iii. Unfulfilled quality expectations

Although not all participants specified that they had standard quality assessment criteria to which they referred when discerning quality OHI, they all described

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locating OHI that failed to meet their expectations in terms of quality. This implies that, in order for this experience to occur, individuals must have quality expectations for OHI and a certain level of confidence in their own ability to discern. Although this was the case for all participants involved, by reading into their descriptions it is possible to see that their specific expectations differed somewhat. Claire explains that she felt that the information was of poor quality because what she had found from different sources did not corroborate:

“...and it would put two or three views that people would write in, or it was Professor somebody or other from New York, or maybe another from Los Angeles who didn’t agree and would always say something quite opposite...Because the variation in ideas, I agree that every illness that everybody has different ideas, but normally you come across basic things that are the same, but some of the things, some of them really contradicted each other.” **(Claire)**

This statement shows that, in line with her search and appraisal approach, Claire seeks OHI from a variety of different online sources and compares them to see if they corroborate. This demonstrates that, as opposed to reading OHI and assuming its validity, she compared multiple types of OHI in order to assess quality.

Edward described an experience whereby he was suffering with an acute ear infection and went online to research treatment options:

“I just typed ‘ear wax treatment’ into Google and you get whole pages of it, headings, and you can just go down the headings and choose the one you like, for example it’s just like ‘ear wax treatment and prevention’ and after that, up comes a page on it. Sometimes you will get a proper paper by you know, a professional by a medical professional, and it could be someone...‘J Bloggs ear wax company’ trying to flog you tools to remove it.” **(Edward)**

This statement shows that Edward had expectations in terms of quality OHI (papers by medical professionals) and had therefore experienced locating information that did not meet these expectations (companies trying to sell him something). Edward also

described these treatments as “a horror story” showing that he used his previous knowledge and existing quality expectations to discern OHI quality.

In the experience where Fiona discussed a time in which she tried to locate OHI regarding a medication that her daughter was prescribed, she stated that she felt that the information was of poor quality because she had expectations in terms of OHI (clear categories of conditions that could be related back to quality information) and what she found did not meet these expectations (people’s opinions of what they thought it might be). This showed that, like Edward, Fiona considered the source of the information when judging its quality. She also went on to provide two further experiences where she had been looking for information about the possible side-effects of her chronic condition. Fiona explained that she judged the information to be of poor quality as she had expectations in terms of quality and what she located did not meet these expectations. Therefore, in this instance, Fiona considered the content and style of the information when judging information quality. These three experiences show that Fiona has more than one quality judgement criteria that she uses when discerning OHI quality.

Although participants gave a variety of reasons why they perceived the information that they located to be of poor quality, they all demonstrated existing expectations in terms of what quality OHI was. This was reassuring because it provides evidence of participants analysing OHI quality as opposed to automatically accepting what they located as valid.

The interview transcripts showed that, although the experience of being left unfulfilled was overwhelmingly negative, it was experienced in a variety of different ways by the participants. Brian explained that finding information which did not meet his quality expectations made him feel like he had not improved his knowledge, whilst Denise stated feeling overwhelmed by the experience. For Fiona, the experience of being unfulfilled made her feel concerned and powerless. This concept of concern will be addressed in a more detailed way within the following constituent.

iv. Confidence and concern

During this experience, participants implied (and in some instances stated) a level of confidence in their ability to discern OHI quality. Interestingly, participants also demonstrated concern for the ability of others to do the same. The problem of being unable to identify poor quality health information was seen very much as a potential problem for others, demonstrating a perceived superior ability to navigate OHI effectively.

In demonstrating her confidence in her ability to locate OHI, Claire explained that she felt reassured that, although there was poor quality OHI available, she knew which information she should take on board. In a further display of confidence, Edward described discerning good quality OHI from poor as being:

“...a matter of experience, and you think there’s somebody trying to flog me something, this makes more sense to me than this one. It’s more judgement.”

(Edward)

Like Claire, Edward clearly also perceived himself to have the “judgement” to be able to effectively distinguish quality OHI. Fiona also demonstrated this through the three experiences that she provided. She explicitly stated that her experience and nature allowed her to avoid this. However, she felt that this would be a problem for others without these same privileges:

“...because I’m fairly rational, and because I’ve worked in health and social care, and because I tend to question things until I’ve got the right answer, I didn’t get hung up on it. But I think it’s very easy to do that.” **(Fiona)**

All participants therefore recognised the potential issues involved with locating poor quality OHI but perceived this as something that would not affect them due to their confidence in their own abilities. For these participants, confidence was experienced in a way that allowed them to be immune from the possible negative implications of finding poor-quality OHI. This confidence was characterised by a perception that others may not have the same abilities to operate on an equal level. Whilst Denise and Brian did not explicitly provide information to describe the nature of their confidence,

Edward explained that, for him, this confidence was due to an awareness of his own ability to show judgement, and an awareness of what the advice from a professional might be. All participants demonstrated that their confidence allowed them to step outside the role of a consumer and view potential hazards for others. It provided a sense of immunity and superiority brought on by judgement and additional knowledge of the situation.

I will now continue to present the analysis for the next OHI-seeking experience: the experience of OHI helping participants understand something better.

3. The Experience of Online Health Information Helping Participants Understand Something Better

Structure

The experience of OHI helping participants understand something better routinely occurs after the individual has had contact with a health professional and the professional provides them with some information relating to their personal health. This experience then continues in a similar way for all OHI-seeking experiences, with an individual identifying a specific health information need. However, in this case, it specifically relates to the information gained during the interaction with the health professional and is explicitly related to the individual's personal health. Therefore, the information deficit was created due to the individual feeling the need for supplementary information to what was provided by the health professional in order to effectively self-manage their condition. They have expectations in terms of the information required, and take responsibility for locating it themselves by looking online. They now enter into a process of online navigation in which they initially use a search engine in an attempt to locate the information they require. This activity leaves them faced with multiple pages of information which they must read through in order to locate the information that they perceive as being able to satisfy their information requirement. The individual perseveres with this process because they feel it is essential that their information deficit is resolved in order for them to effectively self-manage their condition. The individual involved has expectations in terms of the information, and these are met fully by the results of the navigating process. They see this experience as a positive one and trust the information that they

locate. This information empowers them to make decisions about the management of their condition in the future.

The following central constituents have been outlined for the experience of OHI helping individuals understand something better:

Constituents

- i. Identifying an information requirement*
- ii. Taking responsibility*
- iii. Entering into a process
- iv. Fulfilled expectations
- v. Empowerment

As before, the first two constituents have already been discussed and so I will now elaborate on the constituents that are unique to this type of OHI-seeking experience:

iii. Entering into a process

This experience involved the individuals entering into a process of information navigation in order to locate the OHI that they felt they required. During this experience, participants routinely discussed the process of navigating OHI to a greater degree than had been discussed within other experiences. The process consistently began with the use of a search engine tool in an attempt to locate the required information:

“I just went through my usual system, go onto Google, umm, typed in the condition, and uhh up it comes, it’s pages of it...” (**Edward**)

“Well so I put into the search ‘Brachytherapy’, and I can’t remember which website came up, but quite a lot of websites, obviously cancer websites came up for Brachytherapy.” (**Brian**)

“I typed in Fozimax into Google yep, and it came up.” (**Denise**)

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“I just literally wrote the name into Google and you know, brought it up and had a look at, you know, sites.” (**Fiona**)

The way in which this process was described is very similar for all participants, and was specifically described as a “usual system” by Edward, who implied that this part of the process was almost routinely accepted as the manner in which OHI is searched for. It is also notable how many of the participants named Google as the tool they used (no other search engines were named during any of the interviews) suggesting high levels of reliance and trust in this specific search engine. In all cases, the outcome of searching using a search engine was that the individuals were faced with multiple pages of OHI that they had to navigate in order to locate what they felt they specifically required. This showed that, although participants were able to easily locate some information relating to their query, they were also faced with further challenges in terms of searching and appraising the vast quantity of information available. Although participants did not explicitly describe the process of navigation, they stated that they were able to locate the information that they required after being faced with multiple pages relating to their query.

The aforementioned demonstrates that the process of navigation is experienced when an individual is faced with a wealth of information that needs to be navigated in order to locate specific information that is in line with the expectations of the individual. Claire specifically describes this experience as one of “perseverance”, a concept that is echoed throughout other participants’ descriptions. However, Denise experiences navigation in a much more positive way, describing being faced with a wealth of useful information and seeing navigation as a process to obtain a greater web of related information, as opposed to an obstacle that needs to be overcome. However navigation is experienced, the outcome of entering into the process is positive, leading to the fulfilment of expectations.

iv. Fulfilled expectations

One of the defining features of this experience was the fact that all participants noted finding information that fulfilled their expectations in terms of OHI and which they trusted to the extent that they would utilise it to manage their condition. This demonstrates a strong sense of faith in the quality of the OHI that they located. Denise

went into great detail about the comprehensive information that she found, proclaiming “oh yes, it’s all there”, while Edward implied that his trust was formed due to the fact that he only looked at studies as opposed to any other form of OHI. In addition to these demonstrations of trust, Fiona described the information that she located as factual:

“I was looking at factual information, these were sites that were actually giving me factual information about the medication, they weren’t sort of giving me opinions.” **(Fiona)**

Fiona went on to explain that this information went against what she had been told by her health professional, and therefore locating this information had concerned her. This demonstrates the high level of trust that Fiona had in this information being reliable to the extent that it made her question the advice given by her health professional.

Although most participants did not explicitly state their trust of the OHI that they had located, this was implied through their behaviour, specifically by them utilising the information to engage in self-care. Therefore, the participants experienced fulfilment in terms of locating OHI that was trusted to the extent that it could be used practically to help self-manage their conditions. It could be suggested that the information that fulfilled their expectations made them feel empowered to self-manage their conditions.

v. Empowerment

During this experience, the participants located trusted information that they perceived had improved their own understanding of an aspect of their chronic condition. They were then empowered by this information and utilised it in order to self-manage their condition more effectively. The participants showed that increased understanding and knowledge led to feelings of empowerment that allowed them to make decisions about the way they self-managed their conditions. Although this information was adopted in different ways by the participants, it did consistently demonstrate their levels of trust in the information and provide evidence of practical examples of them taking responsibility for their health and care. Brian explained that

finding the OHI helped him understand a form of cancer treatment, and consequently empowered him to make the decision to choose this treatment. Not only does this demonstrate a high level of trust, it also provides an example of how the OHI was utilised in order to facilitate self-management, and demonstrates how it empowered Brian to make informed decisions about his treatment. Denise stated that locating this trusted information provided her with confidence and reassurance to take a drug that she was prescribed:

“It gave me relief...it gave me confidence to think right, I will take this drug. Because I must be honest, I’d had the prescription made up for three months and I hadn’t taken the drug. Because that was just fear.” **(Denise)**

Denise explained how the information gave her confidence and empowered her to make a decision about the treatment of her condition. Denise clearly needed further reassurance in order to accept the advice of a health professional, and this information was able to provide this for her. Fiona also explained that locating this OHI empowered her and provided her with the confidence to have conversations about her condition with her health professional:

“I feel a lot better now by looking it up and saying to her that I thought this might be one of those problems, she didn’t question it, she didn’t say ooh you’re wrong Fiona, she said ‘right lets assume it’s that and try and find if that’s the answer’, and of course it was.” **(Fiona)**

This increased understanding and empowerment allowed her to have the confidence to work in partnership with her health professional and take a more active role in her care.

This experience demonstrates that participants felt that, when OHI seeking led to increased knowledge and understanding of an aspect of their chronic care, they then felt empowered to take an active role in the management of their condition based on the information. This experience demonstrates a clear link between knowledge/understanding and confidence/power that proved a potential benefit to OHI seeking in the individual’s illness condition management. Therefore, during the

experience of locating OHI that helped them understand something better, empowerment was experienced through an increase in personal knowledge and a level of confidence in the information, and the individual's perception of its usability in assisting self-management. Empowerment is therefore something that is experienced when the OHI-seeking process is successful and the information has a positive effect on the individual by fulfilling their expectations and allowing them to become better informed.

I will now continue to discuss the next experience relation to OHI seeking: the experience of OHI increasing an individual's confidence. This experience will act as an interesting comparison with the above because they both describe situations in which the information-seeking process is perceived as successful.

4. The Experience of Online Health Information Increasing Participants' Confidence

Structure

As with more general experiences of OHI seeking, the experience of OHI increasing an individual's confidence occurs when the individual identifies a personal health information need and takes the responsibility to fulfil this need by looking online. At this stage, the individual has expectations in terms of the information required to fulfil this need. By looking online, they are able to locate information that they perceive to be relevant and of acceptable quality, and is therefore trusted by them. They believe that this trusted information meets their requirements in terms of having the ability to remove the existing information deficit, allowing them to have the opportunity to become more informed. The action of becoming more informed has a positive relationship with their levels of confidence, which improve once the information need is removed. Becoming information enabled in this way provides the individual with the confidence to feel able to make healthcare decisions and feel confident in their ability to self-manage their condition. They are therefore empowered by this information and utilise it to manage their own health conditions.

The following central constituents have been outlined for the experience of OHI increasing the individuals' confidence:

Constituents

- i. Identifying an information requirement*
- ii. Taking responsibility*
- iii. Trust and fulfilment
- iv. Empowerment

I will now discuss the constituents that are unique to this experience in more detail. It is important to consider at this stage that two of these constituents are similar to those from the previous experience. Although they will be discussed separately in more detail here, I will expand on this point, including a discussion of similarities and differences within the analysis summary.

iii. Trust and fulfilment

Individuals who lived this experience implied high levels of trust in the OHI that they located while attempting to fulfil their information deficit. Although this was not explicitly expressed, it was clearly shown through the way that they spoke about and utilised the information. For example, when describing the OHI that he located, Brian stated, “I found what I needed”, implying that the OHI that he found met with his expectations. He then utilised this information in the decision-making process. He also implied that he trusted the information and felt that it was valuable in assisting him in the self-management of his condition. Denise stated that she “learnt an awful lot” from the OHI that she located, and continued to explain how she utilised it to make treatment decisions. Claire explained that the OHI that she located, along with the information provided by her health professional, helped her realise and accept that she had the chronic condition Lichen Planus. This demonstrates that Claire must have trusted this information in order to utilise it to make decisions about her health. As previously noted, Edward felt that he was able to self-manage his acute condition entirely based on the information that he found online:

“And I didn’t go to the doctors with that. I read it, and I was quite satisfied that with how long it took uh what the treatment was for it...” (**Edward**)

This also showed great faith in the quality and relevance of the information located and its ability to fulfil his needs in terms of health information.

Participants experienced fulfilment in a variety of different ways. Claire and Denise described the experience of fulfilment as one of reassurance, whereby they looked specifically for information that they felt would help them justify moving forward. In the case of Denise, this was information that allowed her to feel comfortable about taking a new medication, whilst for Claire this helped her accept the diagnosis provided by a biopsy. Brian described fulfilment as “finding what I needed” and made a direct link between this and the increase in his confidence. Edward, on the other hand, offered two different ways of experiencing fulfilment within his two experiences. In the first, fulfilment is experienced as satisfying a general interest in response to broad OHI seeking. In the second, fulfilment is experienced as providing the information that he perceived he required in order to self-diagnose. Although the manner in which fulfilment was experienced varied, participants demonstrated an overall sense of satisfaction with the health information that they found online. Individuals also noted how locating this trusted information helped them feel more reassured about decisions that they had made, thereby increasing their overall confidence. I will now continue to discuss the next central constituent relating to this specific experience.

iv. Empowerment

This experience showed that, by becoming more informed through seeking trusted OHI, individuals were empowered to make decisions about their health and treatment regimes and to self-manage their own health conditions. Brian and Denise both explained how becoming an information-enabled patient gave them the confidence to make decisions about their treatment:

“And I found what I needed. And I was more confident to make the decision to have Brachytherapy” (**Brian**)

“...it gave me the confidence to start taking that drug. Because I had had the prescription for three months and I hadn't had it made up, because I couldn't come to terms with it...so it just gave you that, you know, boost that I needed to kick-start to start taking the drug.” (**Denise**)

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In these cases, becoming more informed about their treatment provided Brian and Denise with the confidence to make decisions about medication and treatment options. This information empowered these participants by making them feel better equipped to handle the important decision-making process. However, in other experiences, becoming information enabled empowered individuals to manage their conditions in different ways. Claire explained that she felt able to “take a more positive view” and work in partnership with her doctor to ensure that she was getting the appropriate treatment for her condition, while Edward stated that locating the OHI empowered him to self-diagnose and manage his acute health condition entirely while also reassuring him that he had not done more damage:

“I suppose it made me feel more confident that I hadn’t done more damage to my foot than I had realised. It was having uhh looked it up on the net...it enables me to be satisfied that what I’d got wasn’t that serious uhhh, in due course with a bit of taking your weight off it and putting peas on it you know, typical sort of thing, it should get better.” **(Edward)**

In all cases, becoming more informed by locating trusted OHI led to participants feeling a greater sense of confidence in their ability to self-manage, and more substantial feelings of control over their health and treatment regime. There was also a distinct sense from these descriptions that becoming more informed increased participants’ perceived ability to work effectively in partnership with health professionals. This is because it allowed these individuals to feel empowered by increasing their knowledge, thus reducing the gap in the information power balance between patient and health professional. As opposed to the health professional ‘holding all the cards’, the patient is provided with confidence through information that allows them to feel empowered.

Within the above experiences, empowerment is experienced as a by-product of increased confidence, and is expressed through practical application of the information that initially helped to increase the individuals’ confidence.

I am now going to move on to present the structure and constituents for the next experience. The following two experiences are ones of sharing OHI as opposed to

seeking it. Therefore, as previously explained, the central constituents for information-seeking experiences (i. identifying an information need and ii. taking responsibility) apply to a lesser degree within these experiences. Although both are implied by the individuals' descriptions of sharing, they are not explicitly described in the above experiences. The first sharing experience that I will discuss is the experience of sharing OHI with a health professional.

5. The Experience of Sharing Online Health Information with a Health Professional

Structure

The above sharing experience occurs in response to an individual taking responsibility for their personal health by seeking OHI relating to an ongoing chronic condition. The outcome of this seeking behaviour is that the individual locates OHI that evokes a level of interest for them. They consequently feel motivated to share this information with a health professional. They assume the right to share, and adopt a partnership approach to working with their health professional in ensuring that they are informed about their health care. They also demonstrate a level of confidence in their ability to interact with the health professional in this way. They reject the traditional hegemonic relationship between patient and caregiver and the information power imbalance, and assume a partnership relationship where information is shared in a multidirectional manner. Once they have shared this information they are in a position where they perceive the reaction from their health professional to their sharing behaviour. The way that each individual describes the reaction as part of the experience suggests that they are aware that health professionals may react differently, and that how the health professional perceives this reaction is a vital part of the experience.

The following central constituents have been identified within the experience of sharing OHI with health professionals.

Constituents

- i. *Taking responsibility*
- ii. Working together
- iii. Perceiving the reaction

I will now continue to discuss the central constituents that were unique to this sharing experience in more detail.

ii. Working together

Despite having a variety of different motivations for sharing, participants all implied that they felt that discussing OHI with a health professional was appropriate and reasonable behaviour, and that they felt able to share this information with them in this manner. This demonstrated that individuals perceived that the role of their health professional involved welcoming information provided by their patients as information-enabled health consumers. Once again this demonstrated a progression from the traditional expectations of a unidirectional flow of information from health professional to patient, and an awareness of this shift in the minds of these patients. This assumption also demonstrated a modification in the expectations of the relationship between patient and professional in the eyes of the individual. These individuals felt that it was their right to share OHI with their health professional in this way, and therefore did so without justification or explanation. Although in most cases this appears to have been an automatic assumption made by the individuals living the experience, Denise states that she was actively encouraged to take a more active role by her general practitioner (GP). Either way, the individuals concerned showed high levels of self-confidence by rejecting the traditional hierarchy of patient and professional. Despite this, the manner in which individuals shared this information varied considerably. For instance, both Fiona and Denise described situations where they shared the information with their health professionals in order to get their advice on the OHI:

“I just went through the things what had come up, and I said you know ‘have you heard about this? Is this, is this you know the things you would recommend? Would you recommend this about Fozimax?’ and I told him it was from the internet.” **(Denise)**

“So I printed this all off and I went to my GP and said ‘Look, I found this information on the web and I assume you know something about it?’” **(Fiona)**

However, Edward explained that he found information online that contradicted previous advice provided by his GP. Despite this, Edward still felt able to discuss this with his GP:

“So I knew either he was wrong, or he was trying to tell me something. So I questioned it, I asked him about it, I said ‘this Roziglitazone it’s, why are we going onto it?’” (**Edward**)

Claire also had different motivations for sharing. She had managed to locate some information relating to her condition that she had found useful, and had taken the printout of this information to the GP with the intention of leaving it there for others to use.

Despite their different reasons for sharing OHI with their health professionals, all of the individuals who had lived this experience demonstrated that they had the confidence to work in partnership with their GP, and also showed an assumption that the traditional paternalistic model for health care was less relevant than it has been in past times.

The above demonstrates that, as part of the sharing experience, participants demonstrated an intention, and assumed a right, to work together with their health professionals. Although in all cases this involved sharing OHI that they had located, the constituent of working together was experienced in two ways for participants. Fiona and Denise described working together with their health professionals as a natural relationship built on respect for each other’s opinions, where both parties welcomed a multidirectional flow of information. Edward and Claire on the other hand both described experiences that involved more of a struggle. For example, Claire discussed sharing the information that she had located not only with the GP, but with the entire surgery, as she perceived the GP was unable to fulfil his role adequately in informing her about the condition. She then encountered what she perceived to be a negative reaction from her GP. During this experience, working together was experienced in a much more forced manner. In a similar way, Edward described challenging his GP’s information power by showing him information he had located that disagreed with information provided by his GP. However, in this instance, the GP

met this behaviour positively, demonstrating a willingness to have the power balance challenged on the GP's part. The reactions of the health professionals to the patients' willingness to work together will now be discussed in more detail.

iii. Perceiving the reaction

Whilst describing the experience of sharing OHI with a health professional, participants went into detail about the reactions that they encountered as a response to sharing OHI. The fact that this was included in all participants' descriptions implies that individuals felt that it was an essential part of the experience. It also suggests that individuals were aware that reactions from health professionals to them as information-enabled patients may vary, thereby identifying this as a possible area of contention. Indeed, reactions from health professionals did vary throughout the experiences. Claire described a negative and dismissive reaction from her GP when she tried to leave some OHI that she had located in his surgery for other patients:

“...he just laughed and didn't take any notice of it.” (**Claire**)

As previously mentioned, this reaction was experienced in response to Claire leaving OHI in a public area of the surgery after perceiving the GP did not fulfil his role in informing her adequately. Claire had a much more negative and aggressive attitude to working with the health professional and, interestingly, experienced a very different response than other individuals. Conversely, Denise, who had been encouraged to information seek by her GP, perceived a positive reaction from him to her sharing OHI. Fiona also described perceiving a positive reaction from her GP, who was so interested that he asked to keep the information:

“...he said ‘can I keep this?’ And yes, yes he did, because I think it's you know, they get a lot of professional information, but I just printed off a simple sheet that said what it was about, and I think he found that useful, and ummm, and, and I said ‘yeah of course you can’ and I just gave it to him because I knew I could get it again if I wanted.” (**Denise**)

Both these experiences demonstrate a sense of mutual respect between patient and practitioner, where their roles within the partnership are clearly defined and accepted by both parties.

Even Edward, who confronted his GP with information that contradicted what he was told in a previous consultation, perceived a relatively neutral reaction from his doctor, with Edward stating, “he didn’t take it too badly.”

These relatively positive reactions demonstrate that the individuals living this experience perceived that their information-enabled status was accepted, and in some cases openly welcomed, by GPs who encouraged a partnership relationship between patient and health professional. Although unfortunately not all experiences were positive, the inclusion of the individuals’ perception of the health professionals’ reaction within their descriptions of the lived experience signifies that it is an important part of the experience for the individuals involved, and that the way the health professionals reacted to them as an information-enabled patient was significant to the lived experience.

In conclusion, for the participants, perceiving the reaction of their health professionals was experienced both positively and negatively. The description suggests that the manner in which the reaction was experienced may be affected by the attitude of the patient and practitioner and the way in which the information was shared. One important theme to arise from within the data for this constituent is the role of respect in developing positive partnership relationships.

I will now move on to discuss the analysis for another sharing experience: the experience of sharing OHI with family, friends and peers at support groups. For the remainder of this analysis, this group will be referred to as ‘others’.

6. The Experience of Sharing Online Health Information with Others

Structure

The experience of sharing OHI with others begins with the individual having located some OHI relating to their condition that they believe to be trustworthy. They have a high level of confidence in the information located and perceive that the information

is potentially of use not only to them, but also for other individuals within their social circle, such as their friends, family members and peers living with the same chronic illness. The action of sharing this OHI demonstrates that, as well as taking a level of responsibility for ensuring that they are fully informed about their health care, individuals also felt a certain level of responsibility towards others within their social circle. This behaviour locates the individual within a culture of sharing, where a support network is formed to help ensure that information is passed on to those who may benefit from it. Therefore, a form of quality control takes place whereby information perceived to be trustworthy is shared within the network. As part of the experience, participants perceive a positive reaction from those they share information with, reinforcing this behaviour and allowing the sharing culture to continue. In some cases, participants imply that a hierarchy of power exists within the sharing networks, with those who are information enabled having greater responsibility than those who are not.

I will now outline the central constituents for this experience.

Constituents

- i. Locating trusted online health information
- ii. Social responsibility
- iii. Positive reinforcement
- iv. A sharing network

The following will provide an in-depth discussion of each of the unique central constituents for this sharing experience.

- i. Locating trusted online health information

The participants described their sharing behaviour in a manner which implied that they had a level of trust in the OHI they had located and that it fulfilled their expectations in terms of OHI. This was experienced in a similar way to the positive seeking experiences of locating OHI that provided the individual with confidence or helped them understand something better. This level of trust and confidence was implied to a certain extent by their willingness to share it with others and their belief that sharing could benefit them. In the first of the two experiences provided by Fiona,

she explained that she shared what she perceived to be “realistic but not frightening” OHI with a friend with the same chronic illness as herself. She also added that she spent time researching this information and was willing to put it on her own website. This description clearly implies that the information Fiona had located met with her expectations of OHI and was deemed trustworthy. In the second experience, Fiona stated that the information that she gave to other members of her support group was “really helpful”, once again implying levels of confidence. Amy made explicit reference to her perception of the quality of the OHI that she located. She described an experience in which she shared OHI with her husband in an attempt to help him understand her chronic condition:

“The information was from the NHS website, so he believed me.” (Amy)

This statement suggests that Amy and her husband both have confidence in this information because it came from what they perceive to be a trusted source.

Locating trusted OHI was a positive experience and an example of what happened as a result of the OHI-seeking process working well. The aforementioned examples demonstrate that there was a relationship between located trusted OHI and sharing. Individuals did not share information that failed to fulfil their expectations in terms of what OHI should be. Although there were similarities within the experience of locating trusted OHI, it was experienced in two different ways for participants. Some located this OHI whilst looking for information relating to their own health and were motivated to share because they felt it would be beneficial to others. Other participants, such as Amy and Fiona, demonstrated specifically looking for information for others relating to their own condition. Either way, what unites these experiences is that the individuals were able to successfully locate what they perceived to be useful OHI, which motivated them to share this information.

I will now continue to discuss the next unique constituent for this experience – the theme of social responsibility.

ii. Social responsibility

Whilst in previous experiences participants demonstrated a sense of personal responsibility for ensuring that they were informed about their health, the descriptions for this experience demonstrated an additional wider responsibility that was perceived by the individuals living this experience. In addition to showing a responsibility to themselves, these individuals assumed partial responsibility for ensuring that those around them in their social circle were provided with the information that they required regarding their health. Participants described sharing the trusted and relevant OHI that they had located with other members of support groups, friends and family in an attempt to assist them in becoming more informed by enabling them to benefit from the information. Denise described a situation in which she was motivated to share with members of a local support group:

“...that’s what the groups are all about Jo, about sharing any information.”

(Denise)

Denise explained that she believed that members of a support group have a responsibility to share any information that they have with others, demonstrating a perception of responsibility towards others’ information status. Fiona described a situation in which a friend explained to her some symptoms that he was experiencing and she took the responsibility to direct him to some OHI that suggested a possible diagnosis. Although this interaction had the potential to cause conflict due to the severity of the diagnosis, Fiona felt that it was her responsibility to discuss this. Fiona (who also acts as a support group leader) described another situation whereby she shared information regarding medications with support group members prior to a visit from a pharmacist, in order to ensure that they were fully informed and could get the most out of the meeting. In both situations, she demonstrated a perceived level of responsibility for ensuring that others were informed by passing on what she perceived to be trustworthy OHI. Amy described a slightly different experience in which she shared OHI with her husband in an attempt to inform him about her condition. This showed that Amy felt that the responsibility for being informed about health care spread wider than health professionals and others living with the condition. She demonstrated that those living and supporting people with chronic conditions also have information needs, and that she perceived those living with the

chronic condition to have a partial responsibility for ensuring that they are fully informed.

The preceding demonstrates that those individuals who attend support groups for chronic health conditions feel a social responsibility to share trusted OHI within the group. It also shows that some participants felt a sense of social responsibility for ensuring that family members were fully informed about their health. This social responsibility was experienced in a number of different ways for participants: as a responsibility towards their family for explaining the side-effects of the condition; as an essential part of the support group subculture; and as a responsibility for ensuring others have the information that they need to effectively self-manage their condition.

The next unique constituent that I will describe concerns the perceived reactions from others to the sharing behaviour and the effect this has on the sharing network.

iii. Positive reinforcement

Patients described perceiving positive reactions from others to their sharing behaviour, in addition to a number of positive outcomes. This positive reaction to sharing OHI with others had the potential to reinforce the sharing behaviour and create an environment where information is shared freely.

Amy explained that her husband trusted the OHI that she showed him and that this achieved her aim of helping him understand her condition through becoming more informed. Therefore, by sharing the trusted OHI, Amy experienced a positive reaction and positive outcomes. In Denise's first experience, she described perceiving a positive reaction from the members of her local support group with whom she shared the OHI:

“...they were quite delighted, and some of them said ‘Have you got any printouts Denise?’” (**Denise**)

She also stated that she encountered a similar reaction when sharing OHI with another local support group:

“...I think they were interested, very interested, they wanted to see the end product...” (Denise)

Fiona also perceived positive outcomes and a level of interest from the friend that she shared OHI with. As she explained, not only did he enquire with interest about how she found the information, but also that her sharing this information resulted in her friend being diagnosed with a chronic condition that had been left uncontrolled for eight years. In a second experience, she described perceiving her sharing behaviour to be “really helpful” and stated that quite a few of the support group members were interested and said that they would go and look the information up.

The positive reinforcement of the participants’ sharing behaviour had the potential to help establish a forum where people felt able to share OHI with those around them whom they felt that it could be of use to. They perceived sharing to be an activity that helped others and something that others were grateful for, thus providing them with the reassurance and confidence that this type of behaviour was appropriate and reasonable.

These examples show that positive reinforcement was experienced in a variety of different ways for participants. For Amy, it was experienced as her husband trusting the information and understanding her situation better, whilst for Denise positive reinforcement was experienced purely as interest in the information. For Fiona, on the other hand, positive reinforcement was experienced in terms of helping a friend receive the treatment that they needed to improve their health and wellbeing. Despite this, all participants demonstrated perceiving positive reactions from others, which reinforced their behaviour and deemed it acceptable within the social sharing network.

The next constituent will describe this social sharing network in greater depth.

iv. A sharing network

During this experience, feelings of social responsibility and the positive reinforcement of sharing behaviour contributed to the construction of a social sharing network in which OHI was freely exchanged. One of the features of the sharing network was that

it encompassed a form of ‘quality control’, where only information that was perceived as trustworthy and relevant was passed through. Many of the descriptions also provided evidence of an information power hierarchy within the network, where OHI seekers had an additional level of responsibility to ensure that others were fully informed. In Denise’s first experience, she explained that not everybody had access to the information that she had found, therefore increasing her perceived level of responsibility to share:

“Well, a lot of the [support group A] are much older, and they don’t use the internet. I’m not saying that they haven’t got the intellect to use the internet or anything like that, there’s no condemning, it’s just not part of their lives at this moment in time, so they were quite delighted, and some of them said ‘Have you got any printouts Denise?’, so I said ‘Well I’ll print out for you’ and so the next time we met, I handed that on.” **(Denise)**

Denise saw age as detrimental to people’s ability to seek OHI, leading to them being reliant on others within the sharing network. This was interesting because Denise herself was 71 years old at the time of the interview, although she talked as if she was set apart from this group of older adults. The notion of immunity was similar to that noted during the experience of locating poor quality OHI, where participants saw it as a potential issue but saw themselves as immune to it due to the high confidence they had in their ability to locate OHI.

Denise also described a similar situation through her second experience in which she felt responsible for providing a service in the form of OHI to members of another support group:

“...they wanted to see the end product, but they didn’t really want to go ahead themselves, they wanted, you know if you could get me a copy I’d be very, very interested and that, that’s what the groups are all about Jo, about sharing any information and you’ve got to judge your audience haven’t you, and you’ve got to realise you know, you mustn’t condemn, you mustn’t, you take them for what they are, and if they just want the information on a piece of

paper to tell them how good it is, and it's not difficult to get going, you know umm then yeah.” **(Denise)**

Through her two experiences, Fiona also demonstrated her role as an empowered information provider within the sharing network. In the first, she explained how she provided information to a friend and urged him to seek a health professional's opinion and explain to them that he had spoken to “somebody who runs a diabetes support group”. This suggests that Fiona is aware that her information-enabled status positioned her in a role of responsibility and power. In her second description, Fiona explained how she took the responsibility to ensure that her support group members were fully informed prior to a talk from a visiting pharmacist in order to guarantee that they got the most out of the meeting. She also demonstrated a perceived information hierarchy that existed as part of the group:

“Well quite a few of them you know said ‘Ooh I'll go and look that up’ and while some wanted to go and look up more, others just accepted that because they don't use the web and think that's the interesting thing that if you...if you say ‘Ooh I'll look this up on a web’ some people say to you ‘Ooh have you got a link that I can use’ OK? And other people say ‘Oh I don't use the web’.” **(Fiona)**

These experiences demonstrate that individuals within the sharing network performed different roles and had different levels of responsibility. Specifically, these descriptions intimated that individuals who sought OHI had a higher level of responsibility for ensuring that those who perhaps didn't have the internet had the privilege of OHI that was perceived to be useful and trustworthy.

In summation, the OHI sharing network was experienced in different ways for participants. Amy and Fiona both described the sharing network as a relationship existing between themselves and one other whom they perceived as needing to understand something better. Denise and Fiona on the other hand experienced the sharing network as sharing with a group of individuals (support group) whom they believed could benefit from the OHI. Throughout both Fiona's and Denise's experiences, it was clear that a hierarchy of information power exists, with them

elevated to a position of power. During these three experiences, the individuals consistently felt that it was their right to share OHI with other people, because those people were, to some extent, reliant on them to ensure that they were fully informed.

I will now continue to summarise the main insights that were identified within the overriding experience and the six more specific ones.

Summary

The overarching experience of older adults seeking OHI can be discussed alongside the more specific seeking experiences (i–iv) as results demonstrated that they all shared the same two central constituents. These constituents were implied as occurring prior to experiences v and vi (sharing experiences).

The experience of older adults seeking OHI occurred when an individual identified a health information need and took the responsibility to fulfil that need.

- In the majority of OHI-seeking experiences, the information deficit related to the individual's own health, although in some cases it related to someone else for whom they felt responsible, such as Fiona's OHI for her dependent daughter.
- It was seen as negative to have a health information deficit and it was experienced in terms of dissatisfaction, worry and/or concern.
- Although one participant described taking sole responsibility for becoming informed, more often individuals described sharing responsibility with health professionals and having an intention to work in partnership with them to ensure positive health outcomes. This demonstrates a shift from the traditional paternalistic hegemony that has existed within the patient–practitioner relationship towards a partnership relationship based on shared information power.
- Those demonstrating feeling responsible for someone else's health suggested the existence of a multidirectional model for responsibility that moves beyond the patient–practitioner relationship.

Stage Two Results

The following six specific experiences can be divided into four seeking (i–iv) and two sharing (v and vi) experiences. Within the four seeking experiences, two were negative examples of what happens when things go wrong (not being able to locate OHI and locating poor quality OHI) and two were positive examples of what happens when things go right (OHI helping to develop understanding and OHI increasing confidence).

The experience of older adults not being able to locate OHI was a negative experience that began in the same way as all other types of OHI-seeking experience. However, it was also characterised by unfulfilled expectations and a prolonged period of being left in the dark.

- An essential part of this experience was that the individual was able to locate some information relating to their query. However, they perceived it as not meeting their specific information needs by failing to fulfil their health information deficit.
- Unfulfilled expectations were defined by preconceived expectations of OHI and the individuals' confidence in their own ability to discern.
- Being left in the dark was experienced as not having the information that they needed to reassure themselves about their condition. This occurred for an extended period.

Similar to the previous experience, the experience of older adults locating poor quality OHI was a negative experience that began in the same way as other OHI-seeking experiences, and continued to be defined by unfulfilled expectations similar to the previous experience. The difference between the two came in that these expectations were exclusively related to the quality of the OHI. This experience was also signified by participants feeling confident in their own abilities to navigate OHI and a concern for others to do the same.

- Although the unfulfilled quality expectations were seen in a negative way by all, the way that they were experienced varied between participants and led them to feel overwhelmed, unfulfilled, concerned and powerless.

Stage Two Results

- Participants demonstrated confidence in their own ability to discern OHI quality, and all had their own criteria that they used to judge this. Despite this, participants also demonstrated concern for others to be able to do the same, suggesting a sense of immunity and superiority.

The experience of OHI helping older adults understand something better was a positive experience that began in the same way as all other OHI-seeking experiences. What was unique about this experience was that, after identifying and taking responsibility for a health information need, participants entered into a process of navigation that led to fulfilled expectations and empowerment.

- The process of navigation occurred when an individual was faced with multiple pages of OHI produced from a search using a search engine tool. They then navigated this information in order to locate what they perceived they needed in order to fulfil their expectations.
- Unlike the last two negative seeking experiences, within this experience expectations were fulfilled. In addition, the individual trusted the information to the extent that they utilised it to self-manage their condition.
- The participants then felt empowered to utilise this information to help self-manage their conditions, and also felt empowered to make healthcare decisions and have informed discussions with health professionals.

The experience of OHI seeking increasing the individuals' confidence was once again a positive experience that began in the same way as all other OHI-seeking experiences. The experience concluded in a similar way to the previous positive experience, with the participants locating trusted information that fulfilled their expectations and led to feelings of empowerment.

- Fulfilment was experienced in a number of different ways within this experience, and included reassuring individuals, satisfying general interests and providing information to self-diagnose.

Stage Two Results

- Participants were empowered by the greater confidence provided by the OHI, thus narrowing the existing information power imbalance between patient and practitioner.

The experience of older adults sharing OHI with a health professional also involved the individual taking responsibility for their health, much in the same as during information-seeking experiences. However, this experience differed because the individual was then motivated to share the OHI with a health professional in a bid to work in partnership with them. During this experience, the individuals also perceived the health professionals' reaction to their behaviour.

- This sharing experience occurred in response to a positive seeking experience.
- Motivations for sharing varied and included wanting advice on the information in order to challenge the health professionals' view and to help inform others with the condition. The nature of the working relationship ranged from mutual respect and perceived information power to a struggle to identify roles within the partnership.
- The perceived reactions from health professionals were an important part of the experience, and ranged from dismissive to encouraging and seemed to rely on the manner in which the information was shared, the existing relationship and the attitudes of both parties.

The experience of sharing OHI with others began with the individual locating trusted information. However, during this experience the individuals felt socially responsible to share this information with others within their social circle. This behaviour was positively reinforced and led to the development of an information sharing network.

- This sharing experience occurred in response to a positive seeking experience.
- The individuals were initially looking for information relating to either their care or the care of individuals within their social circle with the same chronic illness.
- As opposed to personal responsibility described within the previous five experiences, during this experience participants described a wider social

responsibility. It was experienced in a variety of ways, including taking responsibility for ensuring their family was informed about their chronic illness; as an essential feature of the subculture of support groups; and as taking responsibility for ensuring others could self-manage effectively.

- Unlike the experience of sharing OHI with health professionals where the perceived reaction varied, participants who shared with others experienced overwhelmingly positive reactions, which reinforced their behaviour.
- This experience demonstrated the existence of a sharing network that encompassed a form of quality control where only information deemed to be trustworthy was passed through the network.
- Some participants' experiences suggested the existence of an information power hierarchy, with the more information-enabled consumers having greater responsibility for informing the less enabled.

Summary Diagram

In order to further develop the communicative concern of the data presentation, a summary diagram was constructed to demonstrate some of the key phenomenological themes that emerged from the research, and the cohesion between different types of identified OHI seeking lived experiences for older adults with chronic health conditions. Figure 18 demonstrates that the experience of seeking health information online for older adults with chronic health conditions began with the individual identifying a health information need and taking the responsibility to fulfil that need by going online to seek OHI. During this seeking experience, individuals' expectations in terms of OHI were either fulfilled or unfulfilled.

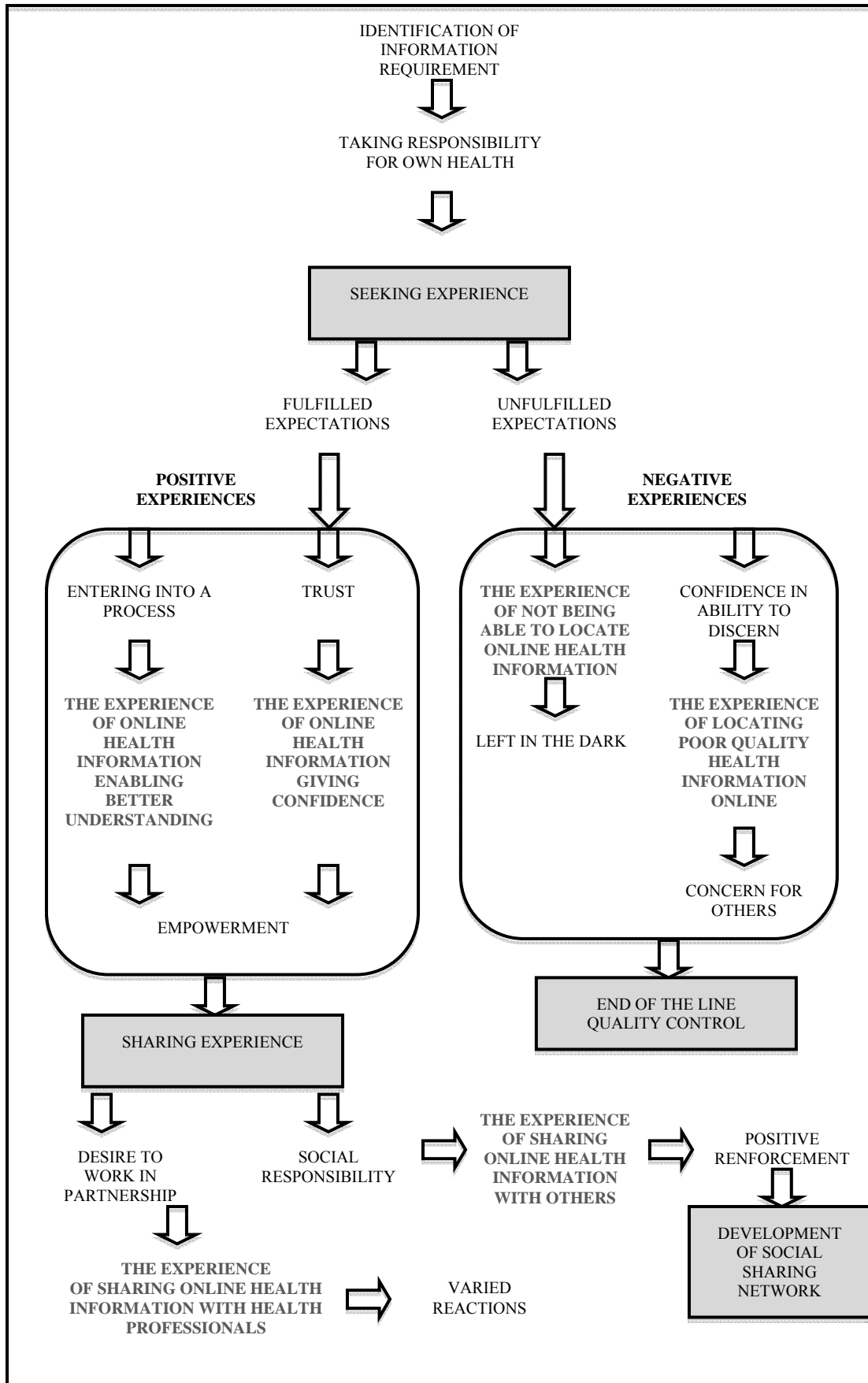


Figure 18. Stage two results summary diagram.

Unfulfilled expectations

If the individuals' expectations were left unfulfilled by the OHI-seeking experience, the experience was perceived as a negative one. Examples of negative seeking experiences were the experience of not being able to locate OHI and the experience of finding poor quality OHI. The experience of locating poor quality OHI was made unique by the individuals identifying feelings of confidence in their ability to discern the quality of OHI, and resulted in the individual feeling concern for others to do the same. However, the experience of not being able to locate OHI was made unique by the experience resulting in a prolonged period of being left in the dark where the information need remained unmet. No OHI was shared during negative experiences, signalling the end of the line of the process. As previously stated, this acted as a form of quality control where poor quality OHI was not shared with others.

Fulfilled expectations

If the individuals' expectations were fulfilled by the OHI-seeking experience, then the experience was perceived as a positive one. Examples of positive seeking experiences were the experience of OHI helping individuals understand something better and the experience of OHI increasing individuals' confidence. The experience of OHI helping individuals understand was made unique by the experiencer describing entering into a specific information-seeking process in order to locate the information that fulfilled their expectations. The experience of OHI increasing individuals' confidence, on the other hand, described the constituent of trust in the OHI, and signified the importance of allowing confidence to develop. Positive experiences ultimately resulted in the experiencer feeling empowered by the OHI. Specifically, they felt empowered to share the information that was perceived as having a positive effect on them with others, such as health professionals, family friends and support group peers. The experience of sharing OHI with a health professional occurred because an individual had a desire to work in partnership with professionals to ensure positive health outcomes. This experience ultimately resulted in the experiencer perceiving a reaction from the health professional, which varied from extremely positive and reassuring to negative and challenging.

Stage Two Results

The experience of sharing OHI with others occurred because the experiencer felt a sense of social responsibility and was therefore empowered to share what they perceived to be positive OHI. This behaviour was positively reinforced by the individuals with whom the information was shared, allowing a sharing network to develop where positive OHI could be shared freely in a bid to help inform all the individuals within this network.

Chapter 9. Discussion

Introduction

The research aims and objectives stated within the preliminary methodology chapter demonstrated that the overarching aim of the current study was to make a valuable contribution to the field of consumer health informatics by improving general understanding of the online health information (OHI) seeking experiences of adults with chronic health conditions. This broad overarching aim was broken down into four smaller research aims in order to specify the precise nature of the study's valuable contribution. The first of these specific aims was to produce a breadth of general information relating to the nature of the OHI-seeking experience for adults with chronic health conditions. The second aim was to provide a depth of focused experiential data by utilising an appropriate phenomenological focus identified by the broad general stage one data. The study's progress in achieving these two aims, along with a discussion of the contribution made by the findings, will make up the first and predominant section of the discussion, termed 'Research Findings'. Within this section, data will be presented concurrently in order to provide a more comprehensive picture of the phenomenon of OHI seeking. The third aim stated within the methodology chapter was to review and develop innovative mixed-methods research techniques in order to make an original contribution to this area of research methods. Therefore, a methodological discussion will be presented as a following chapter in order to provide a full discussion of the mixed-methods research design adopted by the study, along with a discussion of the unique contribution the project made to the field of research methods. This chapter will also provide a reflective discussion of the issues that arose which were related specifically to the adopted research design. It is important to note that, due to the reflective nature of this element of the discussion, a more personal tone will be adopted within the writing compared with previous chapters. Finally, the fourth aim of the research was to produce findings that could be utilised to inform health policy and the training of health professionals in the future, and to provide a justification and focus for further research in the area of OHI seeking. The findings in terms of implications for practice and future research will therefore be presented at the end of the current chapter in a section entitled 'Discussion of Implications'.

Research Findings

It is imperative that the research findings are presented in a way that will help reflect the nature of the sequential mixed-methods study, that will facilitate concurrent discussion in order to present a fuller picture of the phenomenon, and that will coherently tell the story of this methodologically complex research project. In order to achieve these objectives, the research presentation will be structured in a way that will reflect the nature of the methodological approach and honour the findings of each stage of the research, whilst still providing a sense of cohesion between stages one and two. To tackle this task effectively, the research findings will be presented in three sections. The first will provide a discussion of the key findings from stage one of the study in terms of the breadth of information relating to the general experience of adults with chronic health conditions seeking OHI. Within this section, stage one qualitative and quantitative findings will be reflected concurrently. The second section will provide a contextual discussion in terms of the stage one data utilised to guide the focus of stage two of the study. This division will allow for specific discussion of the role of age in the general OHI-seeking experience, and will help discuss the orientation of the stage two research focus. Finally, the third and predominant section of the discussion of research findings will present the key experiential findings from stage two of the study. These findings will be discussed in depth and alongside complementary findings from stage one of the study in order to provide a more complete picture of the phenomenon.

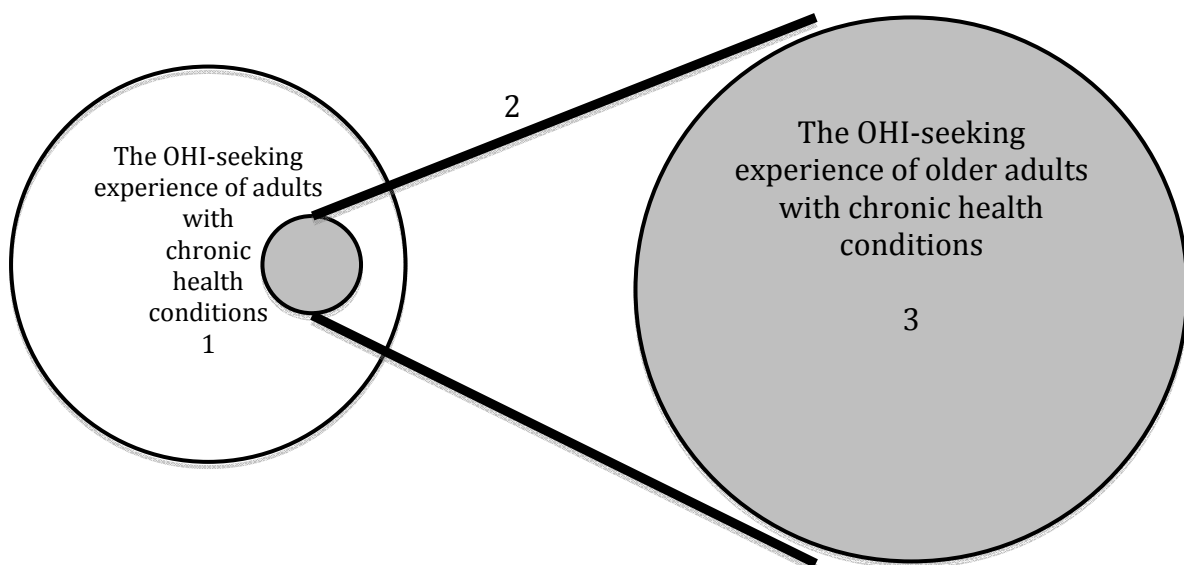


Figure 19. The presentation of the discussion of research findings.

Figure 19 demonstrates how the discussion will reflect the sequential nature of the research by ‘opening out’ the experiential focus of the study. This approach will ensure that whilst findings are kept central to the discussion, none of the rich broad or contextual data is lost, therefore providing a multidimensional discussion from multiple viewpoints in order to reflect the complex nature of the research area.

1. Breadth: The nature of online health information seeking for adults with chronic health conditions

The quantitative and qualitative findings from stage one of the study provide a breadth of information relating to the OHI-seeking experience of people with chronic health conditions. The following section presents a discussion of the key findings of stage one with reference to the relevant background literature, in order to contribute a level of breadth to the overall discussion and satisfy the preliminary aim of the research project.

Prevalence

One of the key findings of stage one relates to the prevalence of internet and OHI usage within the sample. The literature review demonstrates that numerous attempts have been made to quantify the prevalence of OHI seeking, both in the UK (Office of National Statistics, 2007, Office of National Statistics, 2008, Office of National Statistics, 2009) and further afield (Pew Internet, 2000, Harris Interactive, 2008, Pew Internet, 2009). Large-scale US studies suggest that around 75% of the US population now use the internet, with approximately 62% using it specifically to look for health information (Pew Internet, 2000, Harris Interactive, 2008, Pew Internet, 2009).

Although there is limited research regarding the prevalence of OHI seeking within the UK, a 2009 Office of National Statistics survey suggested that around 79% of the UK population have used the internet, and that 42% of these users had used it to look for health information specifically (Office of National Statistics, 2009). Conversely, results from the current study suggest that a notably lower 60% (n=60) of participants had used the internet, with 75% (n=45) of users reporting that they had used it specifically to look for health information. Therefore, comparatively fewer participants had used the internet, but a much higher proportion of those that made use of it did so to seek health information. Specifically, the Office of National Statistics survey (2009) demonstrated that 42% of internet users sought OHI,

compared with 75% in the current study. Possible reasons for this significant variation between the current study and the national survey are the differences in the recruited samples for the two studies. Whilst the national survey was conducted on a random sample of UK households, the current study recruited through support groups in order to specifically locate participants who had been diagnosed with chronic health conditions. Therefore, using these findings, it could be hypothesised that patients with chronic health conditions are more likely to use the internet for the purpose of seeking OHI than other internet users without a diagnosis of a chronic condition as they have greater health information needs. This could explain the difference in prevalence of OHI seeking between the two samples. Despite the fact that OHI usage was higher within the current study compared with the National Statistics Survey (2009), results demonstrated that general internet usage was much lower in the current study. This finding could be justified as being due to the high mean age of participants within the sample: 63.41 years (range=30–89 years, SD=2.58, mode=75, median=64); the current study and previous UK research has demonstrated that older adults are less likely to use the internet than their younger counterparts (Office of National Statistics, 2009).

The non-usage questionnaire requested respondents provide details of what would make them more likely to utilise OHI. A number of participants noted that social web interventions might assist them in using OHI, such as consumer ratings systems and lists of approved websites. It is assumed from these responses that these non-users were unaware that this information is now available and that they are unsure of the appropriate sites to use. This demonstrates the importance of educating adults with chronic illness regarding the quality assessment and navigational tools that are available online through sites like patient.co.uk and discern.org.uk.

Barriers to online health information

Statistical analysis of demographic factors that influenced OHI seeking revealed that individuals who sought OHI were significantly more likely to be younger ($U(98)=518.5, p<0.01$), more highly educated ($U(98) 634.5, p<0.01$) and more frequent internet users ($U(98) 128.50, p<0.01$).

The relationship between education and OHI seeking confirms the findings of previous studies cited within the literature review which state that more educated individuals are more likely to engage with health information seeking via the internet (Brodie et al., 2000, Cotten and Gupta, 2004). Suggestions have been made that this effect could appear because less educated individuals have lower incomes (Cotten and Gupta, 2004) and are less likely to own a home computer (Brodie et al., 2000). However, as stated within the literature review, the reduced cost of high-speed internet within the UK has reduced the potential for socio-economic disparities in home computer ownership. This has also been reflected by UK national statistics, which suggest that 70% of UK households now have an internet connection compared with only 46% in the first quarter of 2003 (Office of National Statistics, 2003, Office of National Statistics, 2009). Therefore, the presence of an education divide within stage two was extremely surprising. The limited data collected in this area is one of the study's limitations. By including additional questions within the questionnaire to determine economic status and computer ownership, this argument could have been further developed in order to provide a more complete picture of the barrier of low education.

Although the positive relationship between general internet usage frequency and OHI usage was not discussed within the literature review, it is common sense to suggest that those who more regularly use the internet are more likely to have used it for the purpose of seeking OHI. This is expected because the internet is more likely to be a significant part of their life and the way that they locate information. Therefore, it is unsurprising that this factor had such a strong effect on OHI usage.

The relationship between age and OHI seeking will be discussed in more detail within the contextual discussion.

Outcomes of online health information seeking

Stage one data demonstrated that age, education and internet usage levels were all shown to have a multiple effects on the outcomes of the OHI-seeking experience. Younger, more highly educated and more frequent internet users were more likely to share OHI with others, as well as being more likely to perceive the positive outcomes of the OHI-seeking experience, such as confidence in healthcare decision-making and

confidence engaging in discussions with health professionals. A possible explanation for why older adults were less likely to share OHI and perceive the positive outcomes of the OHI-seeking experience could be that older adults are less willing to take responsibility for their health and treatment regimes or engage in the tenets of the partnership model, such as sharing information with others, engaging in joint discussions and shared decision-making (Belcher et al., 2006). Therefore OHI seeking would be less likely to evoke the same levels of confidence in taking responsibility for their care for older adults compared to their younger counterparts. Previous literature has suggested that older adults are more likely to demonstrate an intention to defer responsibility to healthcare professionals (Coulter, 1999) and take a less active or involved role in their care than younger individuals (Arora and McHorney, 2000, Davis et al., 2007). Based on the previous literature and findings from the current study, it could be hypothesised that older adults were less likely to perceive increased confidence to operate as an expert patient because they were less inclined towards behaving in this manner than younger individuals.

Although the preceding literature demonstrates a possible explanation for a link between age and the nature of the OHI-seeking experience, it does not help us understand the effect of education on the OHI-seeking experience. However, analysis of statistical stage one data demonstrates a highly significant negative correlation between age and educational status ($r(98) = -.456, p < 0.01$), explaining that the effect of education may be linked to that of age. It could also be hypothesised that education level and experience in using the internet may have an impact on the overall confidence that patients have in their general information seeking and processing abilities, thus facilitating the individuals' perceived confidence to share OHI with others and to use it to engage in discussions and make decisions about their health. Further stage one results support this concept by demonstrating a link between respondents' confidence in their ability to assess OHI quality, their education levels ($U(42) = 111.5, p < 0.01$) and their general internet usage levels ($U(42) = 143.5, p < 0.05$). Future studies should concentrate on developing and testing the aforementioned hypothesis in order to ascertain why individuals encountered different levels of perceived effects of OHI seeking.

Locating online health information

The literature review demonstrated some examples of the limited research that has been conducted into the manner in which individuals seek OHI (Pew Internet, 2000, Eysenbach and Kohler, 2002, Sillence et al., 2007, Harris Interactive, 2008). These studies demonstrated that patients were able to easily find OHI (Eysenbach and Kohler, 2002, Sillence et al., 2007) and frequently used tools to assist them, such as search engines (Pew Internet, 2000, Harris Interactive, 2008) and referrals from others (Pew Internet, 2000). The results from the current study reflect these previous findings, with the majority of participants agreeing that it was easy to find OHI relating to their condition. Specifically, previous literature suggested that between 65% (Harris Interactive, 2008) and 81% (Pew Internet, 2000) of OHI seekers used search engines, which reflects the current study's figure of 77.8% (n=35). Further stage one statistical data shows that 33.3% (n=15) located OHI through referrals, confirming the social nature of OHI seeking (Murray et al., 2003, Pew Internet, 2009).

Assessing online health information quality

Further analysis of the stage one data demonstrated that the majority of usage participants (64.5%, n=29) felt that the quality of OHI needed to improve. Although this finding concurs with previous research (Health on the Net Foundation, 1999, Pew Internet, 2000, Health on the Net Foundation, 2002), it presents conflicting findings to a more recent US large-scale survey which demonstrated that the overwhelming majority of OHI consumers believed that the health information they obtained via the internet was reliable (Harris Interactive, 2008). Possible reasons for these disparities in findings could be the geographical location of the two samples (US and UK), and that the current study was conducted on support group members with chronic health conditions. It could be hypothesised from this data that adults with chronic health conditions are more likely to have concerns about the quality of OHI. This could be speculated based on the assumption that they were seeking OHI about a condition regarding which they had expert knowledge and were therefore more likely to be critical of this information. In addition, participants seeking information relating to the ongoing self-management of a chronic condition as opposed to speculative information may have higher standards in terms of OHI due to the possible serious implications of finding poor quality OHI.

Interestingly, despite the fact that the majority of participants demonstrated that they felt the quality of OHI needed to improve, over half of the respondents also felt able to accurately assess the quality of OHI (56.8% (n=25)). This finding reflects the limited amount of previous research cited within the literature review which demonstrates that, although patients' search and appraisal strategies do not tend to comply with traditional quality searching strategies (Eysenbach and Kohler, 2002), participants are able to search and appraise OHI quality effectively (Eysenbach et al., 2002, Sillence et al., 2007). These findings suggest that patients are aware that not all OHI is of high quality and that they have confidence in their ability to discern this. This is a positive finding because it demonstrates a sense of awareness regarding the issue of poor quality OHI and a confidence in dealing with it effectively for the majority of participants. The open question data from stage one allowed a deeper understanding of the manner in which participants assessed the quality of OHI. These qualitative findings demonstrated that participants cited a number of specific quality assessment criteria and emphasised the importance of common sense and judgement in discerning quality OHI. Despite these positive findings, research cited within chapter one demonstrates that, although participants may state that they utilise a specific set of criteria, the experience may be very different in practice (Eysenbach and Kohler, 2002). Eysenbach et al. (2002) noted that, although the majority of participants in their observation study noted the importance of the source of OHI, none actively checked the 'about us' section of the site under practical supervision. This research highlights a potential limitation of the study by assessing patients' search and appraisal strategies through questionnaires as opposed to participant observation. It may be more appropriate to assess search and appraisal skills through naturalistic or lab-based observation. However, despite this drawback of the current study, results demonstrated that over half of participants had a general level of awareness of how to search and appraise OHI, and had confidence in their ability to do so.

Despite 56.8% (n=25) of participants stating that they had confidence in their abilities to search and appraise OHI, 43.2% (n=20) did not share this confidence. No additional questions were asked relating to why these individuals felt a lack of confidence in their abilities, or what their recommendations might be for improving

their confidence in assessing OHI quality. This has been identified as an additional limitation of the stage one questionnaire. The inclusion of further questions regarding this within the questionnaire would potentially have provided rich findings to complement the existing data, and which could have implications for practice. However, further statistical tests did confirm that those who did not perceive having confidence were more likely to have a lower educational level than those with confidence in their appraisal ability ($U(42) 111.5, p < 0.01$). This helped demonstrate a possible link between education and confidence as previously hypothesised.

Usage participants were asked to outline what they felt would help improve their ability to assess OHI. Overwhelmingly, respondents demonstrated that they felt they needed advice from health professionals to help them locate quality OHI:

“Suitable websites to be provided by doctor.”

“Doctor would give information of a website that is recommended by a health professional.”

Participants also stated that they felt advertising on wards, a definitive list of NHS supported websites, advice from their surgeries and leaflets containing details of recommended websites would be useful in helping them locate quality OHI. These findings support the literature which suggests that additional strategies are needed to ensure that patients can locate relevant OHI and effectively appraise it for quality (Murray et al., 2003). As suggested within the patients' responses, the literature demonstrates that health professionals need to be able to direct patients to sources of good quality consumer health information, including health-related websites (Shepperd et al., 1999). This finding not only confirms suggestions made in previous literature, but also demonstrates implications for the health service and professionals in terms of their roles in ensuring patients locate high quality OHI. It also demonstrates that patients wished to engage in a partnership relationship in order to ensure that they can locate quality OHI.

The role of health professionals

A further key finding of the stage one results was that health professionals were cited as the main source of health information for those who used OHI (64.4%, n=29) as well as non-users (61.8%, n=34). This finding suggests that patients were using OHI as a supplement to information from health professionals, as opposed to replacing professionals as the primary source of health information. This research finding reflects the literature which states that only a very modest number of patients substitute the doctor's advice with OHI (18%) (Fox and Rainie, 2002), with the majority of patients combining this OHI with information from health professionals to effectively manage their care.

Awareness of online health information

Finally, the open question data from stage one led to the discovery of a surprising and rather concerning finding. Qualitative responses to the reasons non-seekers had never used OHI revealed that a number of respondents were unaware that health information was available on the internet. Responses included:

“Unaware online health information available.”

“Never heard of it before.”

In addition, another respondent noted that they would have a go at using OHI now that they had been made aware that it existed. This finding is extremely surprising and pertinent because it demonstrates that some individuals may fall short of the digital divide for reasons that could easily be prevented. Although the literature cited within chapter one demonstrates numerous demographic and situational factors that may contribute to the digital divide (Brodie et al., 2000), these studies fail to address the idea that in this information age some people may not even be aware that the internet could be used to access health information. This finding provides an example of the huge disparities that exist between individuals' general understanding of the internet and its potential in terms of health. Whilst academics and policy makers discuss the potential role of pioneering new technology within a health care setting, we seem to be failing on a basic level to ensure that fundamental awareness of OHI is widespread. Accountability for this failure must also be accepted by health professionals who are

not actively encouraging or informing patients about OHI to the extent that is deemed appropriate by relevant literature (Morahan-Martin, 2004). If they were consistently actively recommending OHI to patients, this situation could be avoided, and all NHS patients within the UK with chronic health conditions would be aware of the possibility of seeking health information via the internet.

The following section will now discuss the stage one findings in terms of the unique experience of older adults seeking OHI, in order to provide a sense of context for the focused experiential data.

2. Context: The role of old age in the online health information-seeking experience of adults with chronic health conditions

Prior to the discussion of the key aspects of the OHI-seeking experience for older adults, this section will provide a brief explanation of the context of the phenomenological study in terms of the stage one data that helped identify the focus. As previously stated within stage one findings, the quantitative data demonstrated that individuals who sought OHI were significantly more likely to be younger than those who did not. The literature confirms that age potentially acts as a barrier to general internet usage as well as OHI-seeking (Brodie et al., 2000, Cotten and Gupta, 2004, Office of National Statistics, 2007, Office of National Statistics, 2008, Office of National Statistics, 2009). The stage one findings confirmed this barrier by providing evidence of a highly significant negative relationship between age and general usage, as well as OHI usage ($U(98) 518.5, p < 0.01$). Brodie et al. (2000) suggest that the negative relationship between age and general and health specific internet usage could be explained by the fact that older adults were found to be significantly less likely to own a home computer or have access to one in the workplace (Brodie et al., 2000). Their research demonstrated that, once individuals owned computers, the effects of the digital divide in terms of age disappeared. In fact, UK national statistics suggest that around 70% of UK households now have internet access, a figure that is growing year on year in line with low price, high speed connections (Office of National Statistics, 2009). Therefore, these findings would suggest that the age divide is decreasing. On reflection, the inclusion of a parallel question regarding computer ownership on the usage and non-usage questionnaires could potentially have allowed me to identify reasons why older adults were less likely to use OHI. However, it is

important to add that, despite this finding, recent research has shown that the largest increase in proportion of those accessing the internet were older adults (Fox, 2001, Office of National Statistics, 2009).

Further stage one qualitative data from the non-usage questionnaire demonstrates that some participants who had not used OHI in the past saw age as a barrier to them engaging with OHI behaviour:

“...at my age see little point.”

“Too old.”

This concept of being too old for the internet and OHI is not a new one and, as stated within the methodological justification, numerous studies cite similar findings (Gustafson et al., 1998, Stanley, 2003, Turner et al., 2007). In addition to the explicit references to age, numerous participants cited functional and physical problems as additional barriers to OHI seeking. These ailments are generally associated with increasing age, and could be used to explain the reasoning behind why individuals perceived age to be a specific barrier.

An additional justification for further research into the experiences of older adults in particular is provided in terms of the stage one data that demonstrates a difference in the OHI-seeking outcomes of older adults when compared with their younger counterparts. As previously stated, analysis of stage one data showed significant negative relationships between age and whether OHI increased confidence in decision-making for users ($U=69.50$, $p<0.01$, $n=42$), whether it improved their confidence discussing their health with professionals ($U=116$, $p<0.05$, $n=43$), and whether users shared OHI with others ($U(43) 144$, $p<0.05$). The previous discussion of these results demonstrated that these findings can potentially be explained by the fact that older adults are less inclined to play an active role in their care or pursue these potential benefits of OHI seeking (Belcher et al., 2006), with many demonstrating an intention to defer responsibility to healthcare professionals (Coulter, 1999) and take a less active and involved role in their care (Arora and McHorney, 2000, Davis et al., 2007).

The stage one data and background literature provide a strong justification for further research into the OHI-seeking experience of older adults. Furthermore, older adults tend to have more significant health information needs because health status generally decreases with age (Nussbaum and Coupland, 2004). It is therefore vitally important that health professionals and those disseminating OHI understand the experience of OHI seeking amongst older adults, so that they can help develop appropriate materials and work effectively in partnership with these individuals. The following section will provide a discussion of what this study has contributed to the understanding of older adults seeking OHI through the key findings.

3. Depth: The online health information-seeking experience of older adults with chronic health conditions

The presentation of the results sections demonstrates the emergence of numerous key findings pertinent to the experience of older adults seeking OHI. Specifically, the analysis of the results from stage two led to the emergence of five key themes within the data. These are as follows:

- i. *Responsibility*: The OHI-seeking experience for older adults is an explicit demonstration of their intention to take control of their health or the health of a loved one.
- ii. *Expectations*: The success of an OHI-seeking experience is judged by the extent to which the resulting information is perceived to fulfil the expectations of the individual engaging in the seeking behaviour.
- iii. *Confidence and concern*: Older adults demonstrate a sense of confidence in their ability to discern OHI, and a concern for others to do the same.
- iv. *Selective sharing*: Positive OHI-seeking experiences lead to individuals feeling empowered to share relevant OHI. Negative experiences are signified by the OHI reaching ‘the end of the line’ and going no further in terms of sharing.
- v. *Reactions and reinforcement*: Positive reinforcement from others leads to the development of information sharing networks. Negative reactions are likely to have the opposite effect and therefore inhibit the development of regular sharing networks.

These five key findings will now be discussed in greater detail, beginning with the theme of responsibility.

i. Responsibility

The experiential data demonstrated that the first major theme of the OHI-seeking experience for older adults was that participants displayed an intention to take responsibility for their health, or the health of a loved one. The specific manner in which participants demonstrated taking responsibility was by identifying an information deficit relating to their health, or the health of a loved one, and taking personal action to become more informed in this area. Therefore, the process of older adults seeking OHI was made meaningful by participants taking personal responsibility for their health, or the health of a loved one. The fact that they assumed personal responsibility for the information deficit demonstrated an autonomous attitude to becoming informed about aspects of care.

The concept of responsibility identified within the data reflects recent themes of government health policy as outlined within the background of this study. Over the past two decades, UK government health policy has continually reaffirmed the importance of patients taking responsibility for their health and treatment regimes (Department of Health, 1998, Department of Health, 2000, Department of Health, 2005, Department of Health, 2009). The Department of Health has also recognised the potentially vital role that the internet can play in informing patients and empowering them to take responsibility, with the development of online services becoming a priority in the modernisation of the NHS. The stage two qualitative findings therefore reflect changes to health policy by signifying that individuals are using the internet as a health information source in a bid to take responsibility for their health, or the health of loved ones.

It is imperative to state that the experiential theme of ‘responsibility’ relates to a phenomenological sense of responsibility to ones own health as opposed to responsibility within a political context. The NHS Constitution for England (DOH, 2010d) outlines responsibilities in terms of what “the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively” (p. 2). This

political definition of responsibility is taken in the context of accountability for ones own actions, and is used as a parallel to irresponsibility or a failure to perform a social duty. It is important to make this distinction between a political and phenomenological definition of responsibility as the experiential data demonstrated a sense of bodily ownership and self-responsibility that was not necessarily related to what the older adults owed to society as a duty or obligation. Furthermore the phenomenological theme was not offered as a parallel to irresponsibility, or in terms of a failure to take accountability for ones own health. Instead it could be defined as an automatic desire to take a degree of control over ones own health. Participants demonstrated this sense of responsibility by ensuring that they were fully informed in order to fulfil a personal sense of duty, as opposed to performing a social obligation for which they were accountable.

In terms of the manner in which responsibility was taken, the lived experiences within the current study demonstrate that individuals took this responsibility to become more informed about their health almost routinely. This was considered to be the case because no justification or explanation was offered for this taking of responsibility, implying a lack of conscious awareness, or an acceptance that this was standard practice in terms of behaviour. The individuals' descriptions gave the impression that taking responsibility for their own body and health was therefore part of an acceptable, natural process. In order to fully understand the nature of this key finding, an additional review of the literature within the field of self-ownership was conducted. The relevant research demonstrates that the manner by which participants assumed responsibility reflects the widespread thought that individuals ultimately own their own bodies and minds and have to manage them accordingly. As outlined by Spiers (1997), responsibility is a behaviour that is entrenched in self-ownership, in individual property rights and in personal awards for good stewardship. The theory of self-ownership is based on the concept that an individual's body is their own property, to which no other individual has a right. This notion can be justified as a basis for a model of self-management because the individual is seen as the person who ultimately has the greatest interest in their own wellbeing (Mill, 1991) and is therefore inevitably best equipped to be responsible for its management. It is also asserted that the assumption of self-responsibility by individuals for their body and health is essential for modern health care to be delivered effectively, because it ultimately

assists in the building of patients' self-esteem in addition to meeting the needs of morality (Spiers, 1997).

In the lived experience of going online to find information regarding a loved one's health, Fiona stated that she used the internet to search for information about a medication provided for her dependant daughter. Fiona specifically noted that she was looking up medication "that I'd been prescribed for my daughter for depression". This statement is very revealing in that it demonstrates a sense of perceived parental ownership over her daughter's body, therefore making her responsible for her daughter's health and treatment decisions.

The act of taking responsibility for becoming informed about their own health demonstrates a level of bodily responsibility and self-ownership by the individuals that contradicts and rejects the traditional notions of paternalism that are endemic within the UK healthcare system (Coulter, 1999). The literature review within the current study demonstrates that the paternalistic relationship between patient and health professional is one in which the professional is identified as the 'expert' and is therefore justifiably entitled to exercise autonomous power over the patient's health and therefore body. These notions are based on the concept of compliance in which the patient relinquishes all responsibility over healthcare decision-making and is refused personal autonomy. Despite the lived experiences demonstrating participants' feelings of autonomy and responsibility for their health, the participants' experiences also demonstrated an intention to involve health professionals in their care and to delegate partial responsibility to them. This finding is also reflected within the stage one quantitative data, which demonstrated that the majority of OHI users cited health professionals as the main source of health information (64.4%, n=29). The concept of sharing responsibility reflects quantitative findings within the literature review which suggest that, whilst there is great concern that patients are using the internet to self-medicate and self-diagnose, only a very modest number of patients substitute the doctor's advice with OHI (Fox and Rainie, 2002), with the majority of patients combining this OHI with information from health professionals to effectively manage their care. Brian provides an example of the perceived nature of the shared responsibility whilst discussing a time when OHI increased his confidence:

“...with the prostate you only saw the person once and then, so you had to make your own mind up then, and that’s why I went on the internet. Because although they gave you a book of what prostate cancer is, and the kind of treatments that you can have, what will happen if you have the prostate removed, or what will happen if you have radiotherapy, or you know the side-effects you would have, and how long you have got to go to have the treatment for, there was no-one to speak to a bit about Brachytherapy, where there was no-one actually to speak to about it so you know, for what I wanted to know I had to go onto the internet about.” **(Brian)**

Brian implied that he perceives the patient and professional both to have a responsibility for ensuring that the patient is informed. However, he also demonstrated the assumption on his part that the decision is ultimately his responsibility as opposed to the professional’s, implying a sense of overarching bodily control and self-responsibility. He also provided an explicit justification of his motivations for OHI seeking in terms of its potential to assist him in making up his own mind and therefore in taking responsibility for his health and healthcare decision-making. Denise also demonstrated self-ownership and a strong sense of responsibility to herself by stating that she felt she needed additional information online after being prescribed a drug by the health professional:

“I just can’t take a drug for the sake of taking. I’ve got to know what this is doing to my body.” **(Denise)**

Despite receiving instructions to take a medication from her health professional, Denise described feeling personally responsible for becoming more informed about the medication before taking it. Results from stage one qualitative data also demonstrate that numerous patients used OHI in order to confirm information provided by healthcare professionals. This behaviour identifies a shift away from the paternalistic relationship that would have seen the professional giving orders and the patient acting with compliance and without question. However, within this experience, Denise takes the responsibility to ensure that the doctor’s advice is in her best interests and will therefore have a positive effect on her body.

As previously noted, the participants' lived experiences demonstrated an intention to take a level of responsibility for their own health care whilst working with their health professional. The participants operated under the specific assumption that they had ultimate ownership of their own bodies; therefore, despite the role of the professional in ensuring that they were fully informed, patients took ultimate responsibility for healthcare decision-making. To assess whether this behaviour complies with the Department of Health's notion of 'partnership', an explanation of the nature of this partnership taken from the Department of Health's response to the Bristol Royal Infirmary inquiry is presented below:

Patients have a right to be involved in decision making and have access to information to support decision making. They have a right to expect that professionals will act in their best interests by actively seeking their consent to treatment and being open when things go wrong. (Department of Health, 2002, p.16)

This definition suggests that, ultimately, professionals will make healthcare decisions despite involving patients in the process. It assumes that, although patients have a right to be informed and give consent, the ultimate responsibility for their care lies with the health professional. Spiers (1997) states that the creation of an environment where patients and practitioners work successfully together is not the same thing as that which the Department of Health wants to term partnership. He criticises the Department of Health's notion of partnership, describing it as an analogue for renewed control in a political marketplace. Instead, he suggests the concepts of shared responsibility and decision-making as an ideological model of the patient-practitioner relationship. This model sees the practitioner as a facilitator and enabler in ensuring that the patient is informed without coercion. Spiers argues that the difference between shared decision-making and NHS notions of partnership are that, while both involve the patient in the decision-making process, the shared-decision model ensures that the patient makes their own decisions based on unbiased information provided by the healthcare practitioner as well as from other sources.

This additional review of the literature demonstrated that the older OHI seekers within this study wished to take a greater level of responsibility for their care than

may be suggested within Department of Health notions of partnership. Participants within the second stage of the current study demonstrated that, although they relied to some extent on the health professional informing them about their health care, the responsibility for becoming informed and making positive healthcare decisions was ultimately their own, thus demonstrating the perceived right to take ultimate autonomy and responsibility for their health.

The preceding shows that, despite the literature suggesting that many patients do not wish to take responsibility for their health care (Arora and McHorney, 2000, Henwood et al., 2003), the older adults who provided the lived experiences engaged in the OHI-seeking experience in an attempt to take responsibility for their health by becoming more informed. This was also overwhelmingly the case for OHI users within stage two of the study. However, qualitative data from the open questions within the stage one non-usage questionnaire demonstrated that some participants had never used OHI because they did not wish to take the same level of responsibility, or did not want to be actively reminded about their chronic health condition. Participants provided the following justifications for not using OHI:

“Because I use my own GP [general practitioner].”

“Had MS [multiple sclerosis] for 32 years – I don’t need or want to know.
Don’t think about MS.”

In addition, stage one quantitative data demonstrated that older adults were less likely to feel that OHI improved their confidence to make decisions about their health care or engage in discussions with professionals. This implies that older adults were less likely to feel that OHI helped them actively self-manage their own conditions.

Older adults within stage two were far more positive about OHI and its ability to improve confidence compared with stage one participants. It could be hypothesised that individuals willing to engage in interviews regarding their OHI-seeking experiences may be more confident about their OHI-seeking behaviour in general and are therefore more likely to take responsibility. These findings also demonstrate the importance of understanding patient preferences before practitioners engage in shared

decision-making. Whilst some patients were happy to engage with OHI seeking in order to take greater responsibility for their care, others were unwilling to accept this responsibility in the same manner. These findings suggest that health professionals need to distinguish how individuals wish to work and adapt their behaviour accordingly, as opposed to forcing them to adopt the role automatically assigned to them based on the Department of Health notion of partnership.

ii. Expectations

Patient expectations were also identified as a key theme of the OHI-seeking experience for older adults. Specifically, the lived experiences demonstrated that the overall success of the OHI-seeking experience for participants was specifically related to the extent to which the OHI they located fulfilled their expectations.

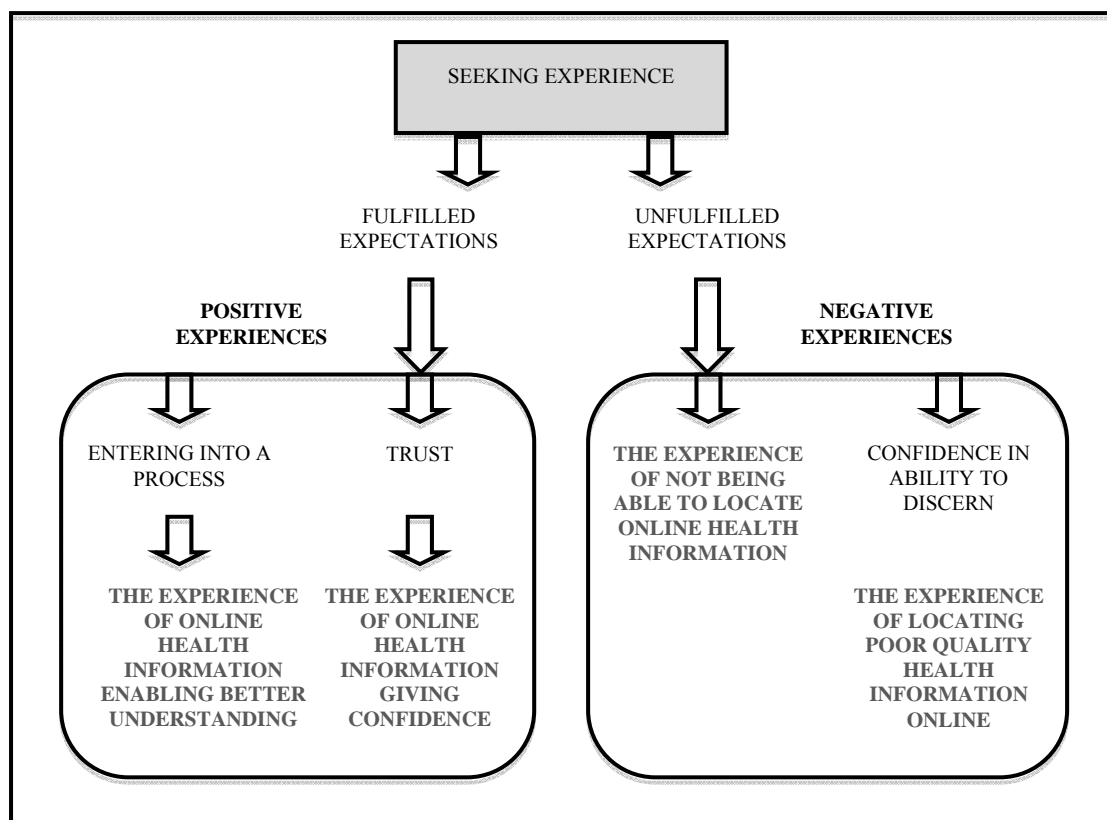


Figure 20. Participant expectations.

Figure 20 demonstrates how the fulfilment of expectations directly relates to whether the overall experience is perceived as positive or negative by the older adults. Examples of experiences perceived to be positive by the participants include experiences where OHI increased their confidence or where it helped them understand

something better. This figure also demonstrates that if participants perceived their expectations to be left unfulfilled by the OHI-seeking experience this led to them seeing the overall experience as negative. Experiences perceived to be negative by participants include the experience of finding poor quality OHI and of not being able to locate the OHI that they required.

A further literature search demonstrated the existence of a relationship between expectations and satisfaction. The Kano model is a theory of customer satisfaction developed in the 1980s by Professor Noriaki Kano and is regularly used to discuss patient expectations in terms of online information (Kano et al., 1984). This theory explains the relationship between customers' expectations and their perceived satisfaction of experiences. According to this theory, customer expectations can be arranged into three main categories: must-be, acceptable and delighters. As outlined by the Kano model, if a customer's basic expectations are not met (must-be expectations), they will not experience satisfaction and will go elsewhere for the services. However, if customers face information that meets all of their expectations, including those which have the ability to surprise and excite them (delighters!), they will be satisfied with the experience. This theory could demonstrate why patients made the link between fulfilled expectations and positive OHI-seeking experiences.

As previously stated, societal changes such as consumerism (Lupton, 1997, Zadoroznyj, 2001), social citizenship (Milewa et al., 1998, Marinetto, 2003) and developments in information technology (Office of National Statistics, 2009) have led to patients having increased expectations of health care generally, in terms of choice and quality of service. The limited research available that deals specifically with patients' expectations concentrates on their expectations in terms of consultations with health professionals. However, this research demonstrates that patients' expectations are central to theories of patient satisfaction (Linder-Pelz, 1982, Zyzanski and Like, 1987, Sitza and Wood, 1998, Kravitz, 2001). Specifically, Linder-Pelz (1982) tested five hypotheses regarding the social psychological determinants of patient satisfaction – one of these being patient expectations. The findings from this study demonstrated that expectations consistently explained most of the variance in satisfaction ratings for patients (Linder-Pelz, 1982). Based on participants' lived experience, the relationship between patients' expectations and satisfaction within the

medical encounter, and customer expectations and satisfaction, seem to be equally reflective of patient expectations in terms of OHI seeking.

The aforementioned data demonstrates that the fulfilment of expectations in terms of OHI was essential for older adults to perceive the OHI-seeking experience as positive. This begs the question as to what the participants' expectations might be in terms of OHI. Within the questionnaire data and lived experiences, adults outlined a number of specific quality expectations and judgement criteria that they had for OHI. Stage one qualitative data demonstrated that participants had expectations of information in terms of authorship, financial motivations, standard of overall writing, balance, simplicity and clarity. Participants also demonstrated a preference for academic, clinical and UK-based information. Despite the fact that patients in this study outlined a number of expectations in terms of OHI quality, the literature suggests that the reality of OHI seekers implementing specific expectation criteria to judge information quality could be very different, even if they stated that they used such criteria to make these judgements (Eysenbach and Kohler, 2002). As previously noted, an observation study demonstrated that, although participants had expectations in terms of the source of OHI, in practice, none of them checked the background information sections of websites when seeking OHI (Eysenbach and Kohler, 2002).

The lived experiences of older adults also demonstrated similar expectations, with participants stating that they specifically sought information based on research or clinical evidence, as opposed to opinions or OHI from sources with a financial motivation. Participants also had expectations relating to the completeness of the information. The following excerpts from participants' interviews demonstrate the nature of their expectations of OHI:

“Well, it was, just named the drug, and the components of the drug, and...but it didn't really tell me, you know what research has been done on the drug, that's that's what I was hoping for...it didn't really give me any information, it didn't tell me what how it worked, what it did and umm so I just didn't find it efficient.” (Denise)

“...there is nothing there that describes what is a hypo and what is a hyper, it talks about hypo and a hyper but it didn’t actually tell you what might happen at that point in time...when I actually looked it up, it talked about people having a hypo and having low blood sugar, but it didn’t talk about the effect that would be.” **(Fiona)**

Both Denise and Fiona had expectations of the OHI based on their specific queries and situations. However, the data from the questionnaires and interviews demonstrated that participants had both general and query-specific expectations in terms of OHI that, when used together, help form their perceptions of a website and therefore ascertain their perceived satisfaction of the overall experience. Figure 21 demonstrates the two types of expectations that were identified by the findings of the current study.

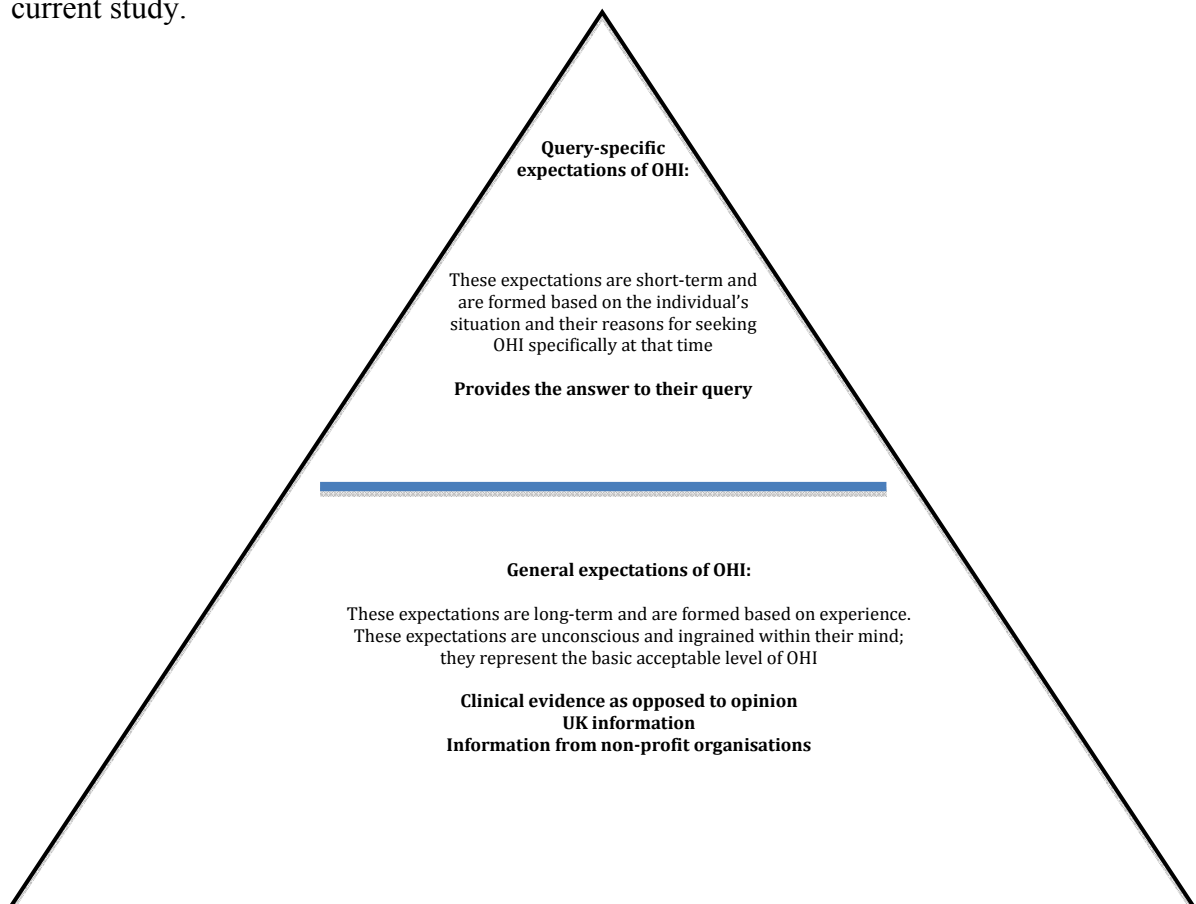


Figure 21. General and query-specific expectations of online health information.

Through the open questions in stage one and the stage two lived experiences, participants expressed a number of general expectations relating to OHI. Examples of general expectations include quality expectations such as a lack of financial motivation, an acceptable standard of writing, simplicity and clarity. They also

include the form of OHI; for example, participants noted expecting to find research/clinical evidence or academic literature to back up statements made by websites. These expectations are long-term and are formed based on the individual's experiences; they are deep rooted in the minds of the individuals. Participants also demonstrated having query-specific expectations; for example, Fiona expected the OHI to discuss the effect of hypoglycaemia (hypos). Query-specific expectations are short-term and are formed based on the individual's situation and their reasons for seeking OHI specifically at that time. It is important to note that general expectations will vary between individuals, as well as query-specific expectations, which vary between and within participants depending on their situation.

In summation, participants demonstrated having both general long-term and query-specific short-term expectations of OHI. If either of these categories of expectations were left unfulfilled by the OHI-seeking experience, participants perceived the OHI experience as being negative. However, if both these types of expectations were met, participants perceived the OHI-seeking experience as being positive. These findings demonstrate that a model of patient expectations and satisfaction of OHI exists for these patients, which reflects the previous literature on customer satisfaction (Kano et al., 1984) and patient satisfaction in consultations with health professionals (Linder-Pelz 1982; Zyzanski and Like 1987; Sitza and Wood 1998; Kravitz 2001).

iii. Confidence and concern

Analysis of stage one and stage two data demonstrated the vital role that confidence plays within the OHI-seeking experience, both generally and for older adults. Qualitative and quantitative findings demonstrated that confidence appeared as a theme in a variety of ways for participants. Confidence was experienced in terms of respondents' perceptions of their own abilities and their intentions to take responsibility, as well as a potential outcome of the OHI-seeking experience.

Although very little research currently focuses on patients' perceived confidence in their ability to operate as OHI seekers, the limited work available suggests that patients lack confidence in their overall ability to judge quality OHI (Murray et al., 2003, Marshall and Williams, 2006). Even though the quantitative findings in stage one of the current study demonstrated that OHI seekers may have more confidence in

their abilities than has been previously stated within the literature, the findings from stage two went one step further and provided depth to this finding. In fact, the lived experiences of older adults seeking OHI demonstrated that participants had overwhelming confidence in their abilities to search and appraise OHI, discern OHI quality and ultimately take responsibility for their own care. It could be suggested that the differences between stage one and stage two findings could be explained by the fact that participants attracted to contribute to stage two of the study may possibly have been more confident in their ability to discern OHI. One of the central constituents of the experience of finding poor quality OHI was confidence in personal ability to assess the quality of OHI, and concern for others to do the same. For example, Claire and Edward both emphasised the importance of judgement in order to discern quality OHI, a personal trait that they both perceived they possessed:

“...because I’m fairly rational, and because I’ve worked in health and social care, and because I tend to question things until I’ve got the right answer, I didn’t get hung up on it. But I think it’s very easy to do that.” (Claire)

Participants demonstrated a sense of immunity to the effects of poor quality OHI and perceived superiority to others in terms of their ability to discern. In addition, participants demonstrated further confidence in their OHI-seeking abilities by stating their intentions to take responsibility for their health and by demonstrating their perceived ability to effectively seek information online to help them do this. In addition, participants also identified that they had expectations of OHI, suggesting a level of confidence to effectively appraise OHI quality and make judgements based on this.

Confidence also appeared as a key theme of the data in terms of the outcomes of the OHI-seeking experience. The notion that OHI seeking has the potential to build patient confidence concurs with previous research (Bass et al., 2006). Specifically, stage one and stage two data confirmed that the majority of participants felt that seeking OHI had increased their confidence in engaging in discussions with healthcare professionals and in making decisions about their personal health and treatment regimes.

As previously noted within the literature, numerous studies have cited the potential for OHI seeking to improve patient discussions with health professionals (Health on the Net Foundation, 2002, Murray et al., 2003, Kirschning and von Kardorff, 2008) by improving patient confidence generally (Murray et al., 2003). Within stage one, participants were asked if they agreed that OHI made them feel more confident in discussing their health and treatment regimes with healthcare professionals. This was to ascertain whether this overwhelmingly positive literature was representative of the current study's sample. Although the majority of participants agreed that OHI did increase their confidence in discussing their health and treatment with healthcare professionals (62.8%, n=27), this percentage was far less than that achieved by the earlier US sample (Health on the Net Foundation, 2002). In addition, further statistical analysis of the stage one quantitative findings demonstrated that there was a highly significant negative relationship between age and whether participants felt that OHI improved their confidence discussing their health with professionals. These findings suggest that older adults are far less likely to perceive experiencing this positive effect of the OHI-seeking experience than their younger counterparts. Despite this finding, a number of the experiences from stage two of the study provide examples of OHI improving the confidence of older adults in terms of discussions with health professionals. These descriptions provide depth to the quantitative findings and help discuss the nature of the confidence.

Although the participants described numerous experiences where they were motivated to share OHI with a health professional, fewer implied specifically that this was because the OHI had a direct effect on their confidence. However, participants did provide examples of when OHI made them feel more able and capable to question health professionals, thus denoting a potential increase in confidence:

“...it enabled me to question anything the umm, doctors or nurses were telling me about it.” (**Edward**)

Although previous research suggests that patients overwhelmingly believe OHI increases their confidence in engaging in discussions with health professionals, the findings from stage one do not agree that this is the case to the same extent. The current study also demonstrates that older adults who seek OHI are far less likely to

perceive that they benefit from increased confidence in engaging with these discussions than their younger counterparts. In addition, further experiential data from this study demonstrates that, although participants were motivated to engage in discussions with healthcare professionals after positive OHI-seeking experiences, there was no explicit description of this seeking experience actually improving their confidence to share. However, a number of patients did note that OHI allowed them to feel more confident in questioning healthcare professionals, therefore rejecting the traditional paternalistic hegemony that has existed within the patient–practitioner interaction.

As cited within the literature review, health information websites are now recognised as an important source of information that contributes towards individuals' health-related decision-making (Pew Internet, 2000, Eysenbach and Jadad, 2001, Baker et al., 2003, Murray et al., 2003, Bass et al., 2006, Sillence et al., 2007, Kirschning and von Kardorff, 2008, Lau and Coiera, 2008). Research by Bass et al. (2003) suggested that the way in which OHI contributes to patient decision-making is by increasing individuals' confidence by equipping them with increased knowledge about their condition. Stage one quantitative findings demonstrated that a majority of 71.4% (n=30) of participants felt that OHI made them feel more confident about making healthcare decisions. However, similar to the results found within the previous discussion, there was a highly significant negative relationship between age and whether OHI increased confidence. Therefore, stage one data suggests that older adults are far less likely to perceive that OHI increased their confidence in decision-making than their younger counterparts.

Despite these results, stage two experiential data provided a number of examples from older adults of how OHI increased their confidence in decision-making. Denise and Brian discussed how OHI seeking made them feel more confident in making decisions about their treatment regimes:

“It gave me relief...It gave me confidence to think right, I will take this drug. Because I must be honest, I'd had the prescription made up for three months and I hadn't taken the drug. Because that was just fear.” (**Denise**)

“And I found what I needed. And I was more confident to make the decision to have Brachy therapy.” **(Brian)**

These findings show that, although older adults may be less likely than younger individuals to feel that OHI improves their confidence in making healthcare decisions, some older adults are able to actively engage in making personal healthcare decisions based on the information that they find online, and can consequently take a more active role in self-managing their chronic health conditions.

In summary, the literature and stage one findings demonstrated the potential for OHI to improve patients' confidence in discussing their health with professionals and in making personal healthcare decisions. However, the results from this study also show that older adults are potentially far less likely to perceive these positive effects of OHI seeking. These important findings can link to the literature which suggests that older adults are indeed less likely to engage in the tenets of the partnership model, such as joint discussions and shared decision-making (Belcher et al., 2006), with many demonstrating an intention to defer responsibility to healthcare professionals (Coulter, 1999) and take a less active or involved role in their care (Arora and McHorney, 2000, Davis et al., 2007). It could be that older adults are less likely to perceive increased confidence to operate as an expert patient because they are less inclined towards behaving in this manner than younger individuals.

iv. Selective sharing

The fourth key theme identified within the stage two experiential data was the unique nature in which older adults engaged in the process of sharing OHI with others. The concept that the process of OHI seeking does not occur within social isolation has been widely recognised by much of the background literature previously cited (Pew Internet, 2000, Murray et al., 2003, Harris Interactive, 2008, Pew Internet, 2009). These studies demonstrate that many individuals refer others to OHI (Pew Internet, 2000), share OHI that they located primarily for themselves (Murray et al., 2003, Harris Interactive, 2008) and seek OHI specifically on behalf of other individuals (Murray et al., 2003, Pew Internet, 2009). Similarly, the stage one findings demonstrated that 44.4% (n=20) of participants printed off the health information that they had located on the internet in order to show others. When asked to provide

details of who they were sharing this information with, participants stated that they engaged in sharing with peers with the same chronic health condition, health professionals, family and friends.

Although it is clear from the above that sharing is a common outcome of the OHI-seeking experience, relatively little is known about what motivates individuals to share, or the precise nature of this behaviour. Phenomenological analysis of stage two data allowed for an in-depth discovery of the commonalities and differences between the seeking experiences in terms of how older adults shared the information that they located. The key finding that arose from this analysis was that, although participants noted different motivations for sharing with peers, health professionals and others, there was one consistent element to all these different types of sharing experiences. This important underlying theme was that participants were only empowered to share OHI in response to positive seeking experiences, where their individual expectations of OHI were fulfilled. Therefore, the experiential data demonstrated that positive OHI-seeking experiences empowered seekers to share information with others such as peers and health professionals. Conversely, the experiential data also showed that negative OHI-seeking experiences where participants' expectations of OHI were not fulfilled signified the 'end of the line' for the OHI. This finding is extremely important in terms of the sharing experience because it signifies a form of 'quality control' inherent within the sharing experience. This form of quality control exists when information perceived to be of good quality and therefore potentially beneficial is passed on to others, whilst information perceived to be of a lower standard or irrelevant is discarded. Therefore, only OHI that meets the expectations of individual seeking in terms of quality and relevance is passed through sharing networks. This finding has important implications for the nature of the sharing experience with peers with the same condition and health professionals.

The studies cited within the literature review demonstrated that health professionals have concerns about the quality of OHI and individuals' ability to accurately locate high quality relevant health information from the internet (Wilson, 1999, Cline and Haynes, 2001). Specifically, a newspaper article cited within the literature review entitled 'Ten ways to wind-up your GP' describes how one professional objects to having to 'wade through' the volume of information presented to him by patients that

is likely to be ‘at best, misleading and, at worst, dangerous rubbish’. The current study demonstrates that, despite GPs’ concerns, participants do control the quality of OHI that they share with health professionals based on their varied individual expectations and the extent to which OHI meets these requirements. These participants demonstrated that they were effectively vetting OHI before they shared it with their health professionals, therefore ensuring that the GP had a reduced chance of having to wade through potentially poor quality OHI. Furthermore, additional literature and stage two findings have demonstrated that participants shared OHI to engage professionals in the process of quality control. Murray et al. (2003) demonstrated that 71% of the individuals who shared OHI with professionals did so in order to get their opinion on the information and therefore include health professionals within the quality control process (Murray et al., 2003). The following statements taken from the participant interviews in the current study describe how Denise and Fiona showed their health professionals the information that they had located online in order to get their opinion on it before taking relevant action:

“I just went through the things what had come up, and I said you know ‘have you heard about this? Is this, is this you know the things you would recommend? Would you recommend this about Fozimax?’ and I told him it was from the internet.” (**Denise**)

“So I printed this all off and I went to my GP and said, ‘Look, I found this information on the web and I assume you know something about it.’” (**Fiona**)

This experiential data suggests that patients make an active attempt to ensure that only information that meets their expectations is shared with health professionals, potentially preventing the need for professionals such as the one cited in *The Times* having to ‘wade through’ large volumes of poor quality OHI. In addition, participants demonstrated a desire to share this information in order to get health professionals’ opinions on its quality and relevance. These findings have important implications because they demonstrate that patients are engaging in processes of quality control, and have an intention to work with health professionals to ensure they are locating useful and relevant OHI.

The key theme that OHI was only shared as a result of fulfilled expectations is also potentially revealing in terms of the sharing relationship between OHI seekers and peers with the same chronic health conditions. The notion of quality control imposed by patients reflects relevant literature which suggests that OHI seekers develop their own unique form of peer review. Recent literature suggests that patients share opinions of and links to OHI through the internet and online digital interventions in order to help others access relevant, high quality OHI (Ferguson, 2000, Ferguson, 2002). Ferguson (2000) describes a ‘new kind of patient’ who finds the best high quality OHI and makes it easier for other patients to locate it online through blogs, personal websites, forums and online discussions. Ferguson explains that these individuals are often highly educated and computer literate, and take responsibility to help those who are perhaps less able (Ferguson, 2000). This notion is also reinforced by stage one and stage two data within the current study. Analysis of stage one qualitative findings demonstrated that those who share OHI are more likely to be more highly educated (U(43) 134, $p < 0.01$), higher level OHI users (U(43) 160.5, $p < 0.05$), younger (U(43) 144, $p < 0.05$) and have higher perceived health status (U(43) 161, $p < 0.05$). This therefore implies that those who perceive themselves as being more capable have a perceived responsibility to help inform those around them who are perhaps less educated or have less experience of using the internet. Despite the fact that OHI sharers tended to be younger, the experiences of older adults seeking OHI demonstrated that all the participants shared OHI with someone else at some point. Denise specifically demonstrates a perceived responsibility towards those who were less capable of locating OHI:

“Well, a lot of the [support group A] are much older, and they don’t use the internet. I’m not saying that they haven’t got the intellect to use the internet or anything like that, there’s no condemning, it’s just not part of their lives at this moment in time, so they were quite delighted, and some of them said ‘Have you got any printouts Denise?’, so I said ‘Well I’ll print out for you’ and so the next time we met, I handed that on.” (Denise)

Although Denise herself was 71 at the time of this interview, she demonstrated a perceived information-seeking hierarchy within the group and a sense of responsibility to share information with others.

Additional research demonstrated the potential role of digital interventions in the process of guiding others to useful OHI. The term ‘apomediaries’ as discussed by Eysenbach relates to human intermediaries who help steer individuals to relevant high quality OHI (Eysenbach, 2007). Being an apomediary involves the use of Web 2.0 applications such as consumer ratings and recommender systems. These systems use human input in the form of reviews and recommendations in order to help guide information seekers to OHI through referrals and to facilitate the sharing of quality judgements. Although participants within the current study demonstrated sharing recommended OHI with others in order to help guide their peers, this was done entirely offline. No participants mentioned the use of any social media applications or digital referral in any of their seeking or sharing experiences. However, patients did demonstrate a sense of social responsibility towards peers with the same chronic health condition and an intention to share positive OHI with these individuals. It could be hypothesised that the sense of social responsibility was partially due to the fact that patients were support group members. Research has suggested that one of the key characteristics of the offline support group is that individuals have a responsibility to share useful and relevant health information with other members (Robinson, 1988). Denise confirms this theory by stating:

“...that’s what the groups are all about Jo, about sharing any information.”

(Denise)

Denise explained that she perceives that members of a support group have a responsibility to share information that they have with others, therefore demonstrating a sense of responsibility towards others’ information status.

The above demonstrates that the theme of information sharing exclusively following on from positive seeking experiences has potentially important implications for general understanding of the nature of sharing experiences. The experiential data suggests that older support group members engaged in a form of offline peer review in order to ensure only potentially beneficial OHI was passed through information sharing networks. This behaviour demonstrates that, although patients revealed a

desire to include health professionals in the process of reviewing OHI, they were also able to rely on peers to ensure that they located high quality relevant OHI.

Although stage two provided a depth of information relating to the OHI sharing experience, there was only a very limited amount of information relating to the social nature of OHI seeking from stage one of the study. Although participants were asked about the experience of sharing OHI with healthcare professionals in stage one, very little data was gathered relating to how people shared with family, friends and peers at the support group. The lack of coverage within this area is a potential limitation of the research study. Now that stage two has demonstrated the importance of this experiential aspect, in hindsight it would have enriched the study to include such questions.

v. Reactions and reinforcement

The final key theme of the experiential data was the vital role that the perceived reactions of others played in the OHI sharing experience. All participants noted specifically how those with whom they were sharing OHI had reacted to their behaviour, and demonstrated how this reaction may affect them and their future actions. Participants implied that positive reactions from others led to the reinforcement of their behaviour and the development of social networks or partnerships in which information could be shared freely in the members' best interests. These networks have the potential to facilitate patient-led care and encourage collaborative working between groups of patients and between patients and professionals. Participants described two types of sharing experiences in which the perceived reactions of others played a vital role. The first of these was the sharing experience with family, friends and, more often, peers with the same chronic health condition.

As previously stated, the literature demonstrated a significant social aspect to the OHI-seeking experience (Pew Internet, 2000, Murray et al., 2003, Harris Interactive, 2008, Pew Internet, 2009), with patients showing a sense of social responsibility towards sharing useful and relevant OHI with others within their social circle. Through the lived experiences within this study, participants demonstrated the

widespread acceptance of this form of sharing by demonstrating the overwhelmingly positive reactions that they perceived when sharing OHI with family, friends and peers with the same chronic health condition. Denise provided explicit examples of the reactions that she perceived from others in response to sharing OHI with other members of her support group:

“...they were delighted.” **(Denise)**

“...I think they were interested, very interested, they wanted to see the end product.” **(Denise)**

Other participants demonstrated experiencing similar positive reactions from sharing, and overwhelmingly so in response to sharing with peers with the same health conditions, who were perceived as grateful for being directed to recommended OHI. The lived experiences of sharing with others demonstrated that participants perceived sharing as an activity that could help others with the same condition and that heralded overwhelmingly positive reactions. This led to the reinforcement of behaviour and the development of forums through which OHI could be freely shared.

Although the lived experiences showed that individuals perceived positive reactions and reinforcement from their sharing with others, the stage one qualitative data demonstrated a less overwhelmingly positive response. Respondents noted perceiving a range of different reactions to the experience of sharing with others, including negative responses such as scepticism and concern.

“Sometimes with interest, sometimes with scepticism, sometimes with shock and anger that this information wasn’t made available to them by their healthcare professional.”

This perception demonstrates the possibility that not all sharing experiences with others such as friends, family and peers are reinforced in the same wholly positive manner.

The lived experiences of sharing OHI with health professionals showed that the individuals' perception of the reactions from health professionals to their behaviour was an essential part of the experience. However, unlike the lived experiences of sharing OHI with others, participants perceived experiencing mixed reactions from health professionals. These ranged from interest and encouragement to complete dismissal of the sharing behaviour:

“...he just laughed and didn't take any notice of it.” (**Claire**)

Those who described experiencing positive reactions from health professionals demonstrated a sense of mutual respect between patient and practitioner, and an acceptance and appreciation of the patient's information-enabled status. These experiences led to the reinforcement of the sharing behaviour and the creation of a forum in which the patient could discuss this information freely.

These varied reactions concur with findings from literature which suggest that patients regularly face hostility from health professionals when they attempt to share OHI (Henwood et al., 2003). The stage one qualitative data also confirmed the fact that patients were not encountering consistently positive reactions from health professionals to their sharing behaviour. Stage one results demonstrated that only 34.1% (n=14) agreed or strongly agreed that healthcare professionals reacted positively to them sharing OHI, compared with 26.8% (n=8) who disagreed or strongly disagreed. Those who agreed justified their answer by explaining that they perceived the impression that this sharing could help improve health professionals' awareness of certain issues, save time and help promote partnership working. Those who did not agree with this statement explained that they felt this may be because of quality concerns and the fact that the behaviour may undermine the consultant's ability.

The key theme of reactions and reinforcement discussed above demonstrates the vital role of perceived reactions from others to the OHI sharing experience. The aforementioned demonstrates that, although friends, family and peers may have concerns about the quality or reliability of OHI, when participants shared OHI with others that they felt would benefit from it, they perceived positive responses to this

behaviour. This positive reaction reinforced this behaviour and made it socially acceptable, enabling the development of a forum in which OHI could be freely shared. This finding demonstrates that individuals are not just working with health professionals to ensure that they are fully informed; they are in fact located in a more complex network of social sharing with peers, friends and family members. These networks are created through positive reinforcement of the sharing behaviour.

Participants also demonstrated a number of positive reactions from health professionals to this sharing experience, which reinforced this behaviour. Unfortunately, these positive reactions were not consistent for all experiences. Both stage one and stage two results demonstrated that patients were likely to encounter varied reactions from health professionals. This finding is really important because it has implications for the emergence of a modernised NHS built around a partnership model and the notion of 'expert' patients. The idea to radically reorganise relationships within the healthcare system is based on the concept that patients and practitioners both share information in order to manage illness successfully. However, this modernisation can only work if both patient and practitioner respect each other's power within the relationship, and if the practitioner reinforces the patient's attempts to take an active role in becoming informed about their health. In other words, if patients perceive negative reactions from their OHI-seeking behaviour, they are less likely to feel comfortable sharing information in this way or work in partnership with health professionals.

Implications of the Research

The discussion demonstrates a number of important key findings in terms of the experience of seeking OHI, both generally and for older adults specifically. The following section will discuss in detail the implications of the preceding findings in terms of practice, including health professionals' training and future research.

Implications for practice

The discussion has led to the revelation of a number of key findings that have possible implications for experienced health professionals, individuals training to enter the field and the organisation of health services in general. Stage one data provided a breadth of knowledge regarding the general OHI-seeking experience for adults with

chronic health conditions, which has the potential to inform practice by outlining how patients are operating as OHI seekers and the barriers that non-users perceive. The quantitative data primarily demonstrated the important role health professionals play in ensuring that patients are adequately informed, by identifying that the majority of both OHI seekers and non-seekers rated health professionals as the most important source of health information. This finding shows that OHI seekers used the information they found online to complement the important role of health professionals. It also implies that, despite suggestions cited within the literature review that OHI usage could lead to lower health service utilisation (Fox and Rainie, 2002), patients could in fact be using OHI to supplement information from health professionals as opposed to replacing it. However, stage two data demonstrated that patients often sought OHI after a consultation when they required supplementary information to make informed decisions. Therefore, despite potentially not reducing reliance on professionals, it may lead to improved outcomes in terms of health, and improved patient confidence in terms of healthcare decision-making.

In addition to patients noting the importance of health professionals, they also suggested an overwhelming desire to involve health professionals in their OHI-seeking experiences in order to ensure positive outcomes. The majority of responses to the open question ‘What do you think would help you assess the quality of OHI?’ demonstrated that most participants wanted involvement from health professionals in the form of recommendations, referrals, or a definitive list of NHS approved websites and leaflets recommending appropriate websites in order to help them locate quality OHI. As outlined within the literature review, the quality of OHI has long been a contentious issue for health researchers, patients and professionals. The findings from the current study demonstrate a possible solution that has the potential to improve patient confidence in OHI seeking, help individuals locate quality OHI and reinforce the partnership relationship between patients and professionals. Put simply, this research suggests that, in order to improve patient experience and health-related outcomes, professionals should endeavour to engage in discussions relating to OHI with patients and help refer them to high quality information. This may help improve the figure of 56.8% (n=25) of participants who felt able to accurately assess OHI.

As previously noted, one respondent specifically discussed how a leaflet outlining recommended websites could potentially help them locate high quality OHI. This finding was also reaffirmed by non-usage findings which demonstrated that some patients would find a list of approved websites useful in helping them use OHI in the future. Furthermore, non-users suggested that Web 2.0 applications such as consumer ratings, if available, might help them locate OHI. The idea of producing a leaflet containing approved health websites and details about sites that offer services such as consumer ratings and quality appraisal tools could help those OHI users and non-users locate quality internet health information in the future. This concept would utilise an information format that the majority of people are comfortable with (printed text and pictures) in order to help improve their confidence in using a format that they may have less confidence in (the internet). In addition, stage one qualitative data also demonstrated a lack of knowledge as a barrier to OHI seeking; therefore increased information may also help patients understand what is available to them online as a patient, and might help reinforce the fact that their information seeking activity won't undermine their health professionals (as perceived by some non-users). Furthermore, some non-users were left short of the digital divide because they were unaware that OHI existed. By engaging in discussions regarding OHI with patients and by providing referrals and possibly printed information regarding recommendations, professionals may be able to improve on the number of patients who feel confident in discussing OHI with healthcare professionals (62.8%, n=27 within the current study), reinforce the partnership relationship in line with UK health policy, help encourage patients to take a more active role in their health care, and reduce disparities in patients' health knowledge.

However, despite these findings, stage one qualitative data also demonstrated that some patients did not wish to take more responsibility for becoming more informed about health care by using OHI. Although this view was held by only a small number of respondents, it demonstrates the importance of professionals understanding patient preferences in order to meet their health information needs effectively.

In addition to the contribution made by the stage one quantitative and qualitative data, the descriptive phenomenological findings of stage two also provided rich information that could potentially make a significant contribution to practice in terms

of helping health professionals understand their patients' experience, identify patients' ongoing needs and make significant quality improvements to care. These descriptions of lived experience have the potential to stimulate reflection by professionals, which could lead to the generation of new ideas (Wilcock et al., 2003). Specifically, the descriptive phenomenological data facilitated the uncovering of essences of the phenomenon of OHI seeking in older adults that have not been completely conceptualised by previous studies. The findings, therefore, have the capacity to help develop knowledge by providing rich descriptions that can help give health professionals an insight into the lives of patients.

In terms of stage two findings, the lived experiences demonstrated a need for professionals to understand that some older adults may perceive a sense of responsibility for their own health and a level of bodily ownership, which must be respected by professionals in order for them to provide high quality care that meets patients' needs and expectations. These findings also suggest that the OHI-seeking experience is intended to contribute to a partnership relationship between patient and professional, whereby both parties hold a level of responsibility. However, the lived experiences also showed that this bodily responsibility contributes to some individuals feeling that, ultimately, healthcare decision-making is their own responsibility. Therefore, this phenomenological data confirmed the implications for practice made by stage one data, by demonstrating that many patients had a desire to work in partnership. However, the stage two data provided more explicit detail about the proposed nature of this partnership from older adults in order to guide health professionals in practice.

The lived experiences could also help develop the knowledge of professionals and policy makers by outlining the important role health professionals play in reinforcing self-management of chronic conditions by OHI seeking. The data demonstrated that health professionals reinforced this behaviour by establishing a forum in which information could be freely shared and a partnership approach could be developed and nurtured. Participants who described experiencing positive reactions from healthcare professionals demonstrated the existence of a sense of mutual respect between patient and practitioner, and an acceptance on the part of the professional of their information-enabled status, thereby reinforcing their behaviour. This experiential

data demonstrated that, in order to promote self-management of chronic health conditions in line with Department of Health policy, policy makers need to consider if professionals are reacting in a way that reinforces this behaviour and the partnership relationship.

Both stage one and stage two data have the potential to inform policy and the training of health professionals by providing a breadth of information regarding the OHI-seeking experience of adults and in-depth experiential data relating specifically to the experience of older adults. Although the small scale of the study is a potential limitation, the findings have enabled the development of numerous implications for future research to help develop knowledge relating to the OHI-seeking experience further.

Implications for future research

Further study is required to demonstrate how far the stage one results can be replicated within a wider cohort of people with chronic health conditions before any further conclusions or generalisations can be made. Conducting further research with a larger sample would also address one of the key limitations of stage one of the current study – sample size. The relatively small sample size has implications for the integrity of the statistics and the manner in which the findings can be utilised practically. To enable more general statistics and generalisations, a much larger cohort would be required.

In addition to this key implication, the discussion of the study's findings uncovered four key areas for future research

- Patient preferences

As stated within the discussion, stage one findings demonstrated that patients had different preferences in terms of their willingness to take responsibility for their health and treatment regimes by utilising OHI. This indicates a potential need for future research to uncover the specific nature of patient preferences and the prevalence of these different attitudinal approaches. In addition, further research should consider what factors contribute to patients' preferences in order to provide a more complete picture of the phenomenon. These findings could help contribute to

future policy in terms of communicating the nature of partnership based on patient preferences.

- The effect of online health information usage on health service utilisation

The discussion explained that OHI seekers lay the same level of importance on health professionals as non-seekers. Therefore, future research should consider whether or not OHI usage is reducing healthcare utilisation or contributing to the overall quality of life of patients. These findings would help inform policy makers in terms of outlining the specific contribution of OHI.

- Participant observation of online health information quality assessment

Stage one and stage two findings demonstrated that the majority of patients felt confident assessing OHI quality and had specific expectations in terms of this form of health information. One of the key limitations of this study is that much of the quantitative data was based on patient perceptions and ratings as opposed to observations. Therefore, future research projects could be developed to observe patients' quality assessment criteria in practice, similar to work undertaken in Germany (Eysenbach and Kohler, 2002) which utilised naturalistic observation, questionnaires, interviews and focus groups in order to ascertain how people were assessing OHI quality.

- The effect of practitioner referral/online health information leaflets

Finally, the study's findings demonstrated overwhelmingly that patients had a desire to work with health professionals to locate high quality OHI. In order to provide evidence of the effects of practitioner referral or other referral interventions such as OHI information leaflets, further research should review the effectiveness of such interventions in order to gather information to inform practice and the future training of health professionals.

The above demonstrates how the study's findings could help justify future research in the area of patient preferences and consumer health informatics. Furthermore, in the context of mixed-methods research, it would be useful to consider how this methodological structure could be applied to other research areas where relatively little is known about the specific nature of the phenomena involved.

Contributions to Knowledge

As well as providing a number of implications for practice and future research, the preceding findings have made a unique contribution to the knowledge regarding how patients use OHI and their preferences in terms of taking responsibility for their health and treatment regimes. These contributions have been separated into five key themes:

- Showing through experiential examples that older adults can use the internet to find useful and relevant health information

Despite stage one findings and previous literature demonstrating that older adults are less likely to engage in the OHI-seeking experience (Cotten and Gupta, 2004, Office of National Statistics, 2009), the phenomenological data from stage two demonstrated that some older adults are effectively engaging with OHI seeking with confidence, and are perceiving positive outcomes of this experience. These findings make an important contribution to knowledge in terms of rejecting perceptions that older adults are “too old” to use OHI, as cited by participants within stage one and previous research (Gustafson et al., 1998, Stanley, 2003, Turner et al., 2007). These findings also make an important contribution to knowledge as the internet has the potential to provide the older generation living with chronic illness with extraordinary opportunities to access useful and relevant OHI. Moreover, the possibilities of OHI are especially great for older adults who are homebound or live in remote areas because it may be difficult for them to access health information by more traditional means (Becker, 2004). It could also have positive implications for the significantly higher than average number of older adults who live with some form of disability that creates an additional barrier to accessing traditional forms of health information (U.S. Department of Health and Human Services, 2002).

- Confirming that patients want different levels of responsibility for their health

The stage one findings demonstrated that, although a number of patients were happy seeking OHI and taking responsibility for becoming more informed about their health, a small minority of patients with chronic health conditions did not share this desire. This key contribution to knowledge helps explain why some people may not utilise OHI and the importance of professionals engaging in discussions relating to patients’ preferences. In addition, this knowledge confirms previous research which suggests

that patients have different preferences in terms of the responsibility that they wish to take for their own health and OHI (Henwood et al., 2003).

- Providing an increased understanding of the online health information quality issue

Stage two demonstrated that one of the key features of the OHI-seeking experience was confidence and concern. Participants demonstrated an awareness that poor quality health information was available online, a confidence in their own ability to discern OHI quality and a concern for others to do the same. This finding could also be seen to a lesser degree within stage one results, which demonstrated that the majority of participants had concerns about OHI quality and had a confidence in their ability to discern. This finding makes an important contribution because many studies have concentrated on the issue of OHI quality (Impicciatore et al., 1997, Health on the Net Foundation, 1999, Pew Internet, 2000, Berland et al., 2001, Cline and Haynes, 2001, Health on the Net Foundation, 2002). Specifically, a systematic review demonstrated that the majority of studies (70%) concluded that the quality of health information was a problem on the internet (Eysenbach et al., 2002). Findings from the current study demonstrated that OHI is potentially less of an issue, as patients demonstrated a sense of immunity to the negative effects of poor quality OHI.

Demonstrating the important role health professionals play for online health information seekers and non-seekers

Stage one and stage two findings confirmed that health professionals are still the number one source of health information for OHI seekers and non-seekers. This is an important contribution because it suggests that OHI seekers may be as likely to rely on health professionals as non-seekers. This has possible implications in terms of health service utilisation and self-management behaviour. This study also made a further contribution by demonstrating that OHI seekers intended to involve health professionals in the OHI-seeking experience in terms of gaining referrals, getting advice on OHI and engaging in joint discussion.

Identifying and describing the social nature of online health information

The current study makes a final contribution to knowledge by confirming the social nature of the OHI experience in line with previous research (Pew Internet, 2009). The literature demonstrated that, in order for patients to effectively seek, evaluate and

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utilise OHI, they rely on interactions with and the support of others such as family, friends and peers, as well as health professionals (Pew Internet, 2009). This research also goes one step further by providing an in-depth description of how information is shared – in response to positive OHI-seeking experiences. This finding demonstrated that a form of quality control was imposed by patients. The study also contributed the importance of reinforcement from others to help establish social sharing networks and partnership relationships where OHI is shared freely.

Chapter 10. Methodological Discussion

Introduction

As specified within the study's aims and objectives, in addition to providing a breadth and depth of information relating to the nature of online health information (OHI) seeking as experienced by adults with chronic health conditions, a further aim of the study was to review and develop innovative mixed-methods research techniques in order to make an original contribution to this area of research methods. In order to effectively handle the study's aims, the research project utilised a pragmatic approach to methodological design that resulted in the adoption of a sequential mixed-methods approach.

As previously discussed, the philosophical approach adopted by this study is methodologically based on reformed notions of complementarity as a motivation for combining research methods to produce work that is both practically and philosophically sound. The theory behind this approach is based on the work of Sale et al. (2002), building on the earlier work into complementarity (Greene et al., 1989, Morgan, 1998) that describes mixing methods so to view a phenomenon using different aspects in order to build up a more holistic picture, therefore justifying the use of different methods. Sale et al. (2002) developed this popular notion of mixing for the purpose of complementarity (as opposed to mixing for the intention of triangulation for the purpose of cross-validation) because they believed that traditional notions of complementarity were not advisable for mixed-methods research if the ultimate goal was to study different aspects of the same phenomenon. They justified this belief by explaining that, philosophically, methods from different paradigms are unable to answer research questions in the same way due to the phenomenon under study failing to be consistent across different methods. They therefore offer a philosophically sound solution to traditional complementarity that acknowledges and respects paradigmatic differences, whilst still allowing for the combination of different methods within a single study. They note the importance of accepting that qualitative and quantitative research will inevitably look at different phenomena within the same research area, and suggest as part of their approach that the phenomenon examined by each method must be explicitly labelled, thereby emphasising the differences that separate qualitative and quantitative research. Using the current research method as an example, the OHI-seeking experience could be

viewed using qualitative methods in terms of the phenomena of ‘lived experience’; and in the case of the quantitative methods, the phenomena could be defined as a ‘measure’. By utilising this approach, I was able to combine qualitative and quantitative methods within a single research project in order to provide a holistic understanding of complex phenomena, whilst still honouring epistemological and ontological differences between paradigms.

Using an innovative sequential mixed-methodological approach has added significantly to this study, both in terms of the design and execution, and by developing current knowledge regarding the integration and applications of mixed-methods research. In order to provide an in-depth discussion of the value of a mixed-methods research design within the current study, this chapter will consider three distinct areas in terms of the contribution. The first of these will discuss what the choice of methodology brought to the study in terms of the value added by the adopted methodology. The second will provide a discussion of the potential unique methodological contribution the project made to the field of research methods in line with the aims of the study. The final distinct area will discuss the practical implications of conducting a mixed-methods research study primarily in terms of the challenges that I faced as the researcher.

The Methodological Value of the Study

During engagement in the pragmatic selection and development of an appropriate and relevant research methodology for the current study, the potential value offered by a mixed-methods research approach was identified in terms of the ability for multiple methods to accurately reflect the complex nature of human experience within a relatively under-researched phenomenon. The use of multiple research methods enabled the exploration of different aspects of the phenomenon in order to provide a more holistic discussion as well as a more appropriate phenomenological focus for the study. A consideration made in hindsight of what specific value a mixed-methods approach brought to the current study is discussed in relation to three distinct areas.

Providing breadth and depth

Primarily, utilising a mixed-methodological approach allowed for the discovery of broad quantitative data relating to the phenomenon of OHI seeking that could be

discussed alongside, and used to complement, the depth of rich experiential data collected as part of stage two. This manner by which the methodological approach added value to the study is justified within the literature in terms of the motivations for mixing to achieve methodological complementarity (Morgan, 1998, Sale et al., 2002). The theory behind this application of mixed-methods research is that, by increasing the number of research strategies utilised within a single research project, it is possible to broaden the dimensions of the project and thereby provide a more holistic and complete picture of human experience (Morse, 2003). The current study was able to provide a more ‘complete picture’ by looking at the phenomena from different angles in terms of breadth and depth, and by producing findings that complement each other and help build a more complex picture of the experience of OHI seeking. Without the inclusion of a predominantly quantitative questionnaire, the study would have been unable to develop a broad description of the OHI-seeking experience. Similarly, without the qualitative stage, the study would not have been able to ascertain the depth of experiential description that helped bring the quantitative findings alive and give them a voice. Thus, both stages and the research offered something different to the study, which would not have been achieved by using a single quantitative or qualitative research method in isolation.

Facilitating multiple forms of expression

Adopting a mixed-methodological approach to the research design that utilised research methodologies rooted within both the qualitative and quantitative paradigms facilitating the use of the relevant discourses associated with each of these types of research. This enabled differing yet complementary styles of presentation to coexist, providing an accurate reflection of the multifaceted nature of the phenomenon being studied. It also permitted a certain level of flexibility and freedom in terms of presentation, assisting a pragmatic approach to form selection and allowing the pursuit of ‘what works’, as opposed to remaining close to the rigidity of tradition. The notion of combining different types of discourse could be adopted within a traditional single paradigm research project, but it lends itself more naturally to a mixed-methods research project which is able to provide additional justification for this presentation style.

In addition, utilising multiple forms of expression has additional implications for the future dissemination and utilisation of the research findings. The use of various discourses allows a level of accessibility to multiple audiences from both the sciences and arts, and potentially allows a greater number of individuals to relate to the findings in terms of their academic and methodological orientation. It also provides the opportunity for increased flexibility when disseminating findings. Put simply, it is possible to present the results based on the orientation and methodological inclinations of the audience, thus improving the general levels of their utility.

Helping maintain a relevant and appropriate focus

The utilisation of a sequential mixed-methods approach meant that the predominantly quantitative findings from stage one of the study could have a practical impact on the focus and design of stage two of the study. This emergence ensured that relevance and appropriateness were maintained to a high degree throughout the research process. By conducting a preliminary questionnaire exploring the measures of breadth of the phenomenon, relevant foci were identified for future research based on experimental findings, one of which was developed within the project. Ultimately, the adoption of a sequential mixed-methods approach helped identify a phenomenological focus that was not initially considered for the research. Without the preliminary stage of the study, the research may have been orientated based on the limited previous literature or the researcher's preferences, as opposed to the relevant phenomena identified within stage one. This can be demonstrated using the following example:

Within the initial study design process, I had consciously envisioned that, based on previous literature, the most likely focus for stage two of the study would be an in-depth analysis of the experiences of adults sharing OHI with health professionals, and expected the stage one findings to orientate the study in this manner. Taking this into consideration, the chances are that, without stage one, the experiential study would have been focused in this direction. This would have followed the work of numerous others in discussing the sharing aspect of the phenomenon. However, stage one allowed for the identification of an even more prominent and under-researched aspect of the overall phenomenon – the experiences of older adults OHI seeking. Without this preliminary stage, a potentially less relevant focus would have been adopted for the phenomenological study.

Therefore, the sequential mixed-methods approach that was utilised within this study allowed for the orientation of an appropriate experiential focus, which could not have been achieved through a single stage research project, thus providing value to the overall study.

The Value of the Unique Contribution to Mixed-methods Research

Despite the fact that the combination of qualitative and quantitative methods within a single study has been common practice within healthcare research over recent years, this relatively modern form of research methodology still requires further exploration in order to establish itself alongside traditional models of qualitative and quantitative research. It is therefore essential that researchers engage with this methodology in new and innovative ways, and that they document their experiences and findings so that mixed-methods research can develop into an equally formulated and accepted methodological option. This study made a unique contribution to the development of mixed-methods research by using a pragmatic approach to mixed-methods research design and utilising a new model of philosophically sound mixed-methods research. It also encouraged the mixing of methodologies uncommonly combined within a single research project in terms of quantitative questionnaires and phenomenological interviewing, and provided a unique template for presentation. Finally, I have personally made a contribution by publicising and promoting my work at national and international conferences (details follow), and by defending the project as a philosophically sound example of high quality research. The previously mentioned contributions will now be discussed in greater detail.

Provides a philosophically sound example of mixed-methods research

This study offers a strong example of mixed-methods research that respects the epistemological and ontological differences between qualitative and quantitative paradigms. This research provides a contrast to the vast amount of research that assumes mixing uncritically, overlooking the many underlying paradigmatic differences (Sale et al., 2002). The justification for mixing within the current study is based on reformed notions of complementarity as a motivation for combining research methods, to produce work that is both practically and philosophically sound (Sale et al., 2002). This approach ensures that each methodological component is kept

separate until the point of integration (discussion), and each stage explicitly labels the phenomenon examined by each method. This process is essential in order to produce philosophically sound research, as the technique emphasises the importance of accepting that qualitative and quantitative research will inevitably look at different phenomena within the same research area.

By adopting a philosophically sensitive approach to the mixed-methods research design, the study made a significant contribution to the body of critically accepted mixed-methods research. It also presents an approach to mixing methods that is potentially more palatable to qualitative and quantitative purists, who are able to identify that their preferred methodological approach has been respected and its unique contribution to the overall research has been recognised.

Provides an example of the opportunities for pragmatism within mixed-methods research

Another way in which this study makes a unique contribution to the field of mixed-methods research is by providing a practical example of the opportunities for pragmatism and methodological freedom within this form of research. The research design that was applied to the current study was adopted because it was viewed as the most suitable method of answering the study's complex research aims and objectives. Too often in research, methodological design is biased by researcher preferences or, in more extreme cases, by the study's objectives being worked around methodological allegiances and preferences. However, within this study, opening up to the possibility of mixing methods allowed a certain methodological freedom that ensured a pragmatic approach could be taken in the design of methods that focused on the important questions within the complex field of research. This has important implications for the study of mixed-methods research and for research methods generally.

Demonstrates an innovative mixing procedure

As well as having important implications in terms of pragmatism, this study offers an original structure for mixed-methods research that is based on the study's aims as opposed to former literature. By adopting an approach that has not previously been documented within preceding research, this study makes a unique contribution to the

field of mixed-methods by providing and testing a new template for mixed-methods research design. It also emphasises the importance of pursuing ‘what works’ within mixed-methods research, as opposed to forcing research to fit a predetermined mould. Many eminent academics within the field of research methods have provided rigid templates and designs upon which mixed-methods research should be based (Morgan, 1998, Creswell et al., 2003, Morse, 2003). Despite the current model demonstrating certain similarities to Morgan’s quan-QUAL model, this design is made unique by the inclusion of open questions within the preliminary stage, therefore offering a unique methodological design that emphasises that mixed-methods research can move beyond traditional models outlined within the literature. Figure 22 demonstrates the innovative mixed-methods research model that was developed in order to tackle the study’s aims and objectives.

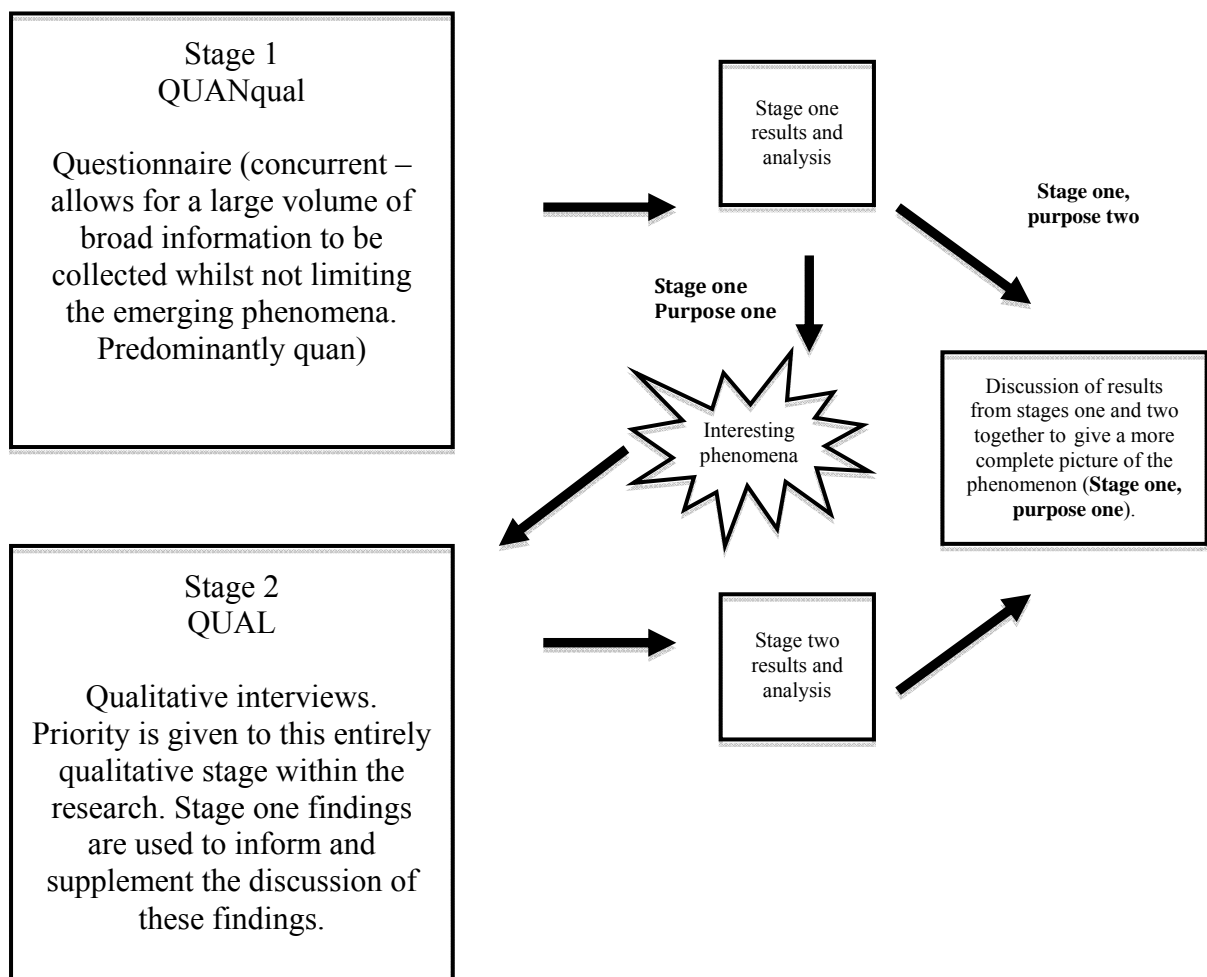


Figure 22. The unique methodological design developed for this study.

Figure 22 demonstrates this study's unique contribution to the field of mixed-methods, in terms of building on the work of other methodologists (Morgan, 1998, Creswell et al., 2003, Morse, 2003) and producing an additional template for future mixed-methods research. It also demonstrates the potential for combining both concurrent and sequential mixed-methods research within a single model in order to maximise the potential of each stage of the research process. Finally, this study has made an additional contribution in terms of its design, by encouraging the mixing of methodological approaches uncommonly combined within a single research project: heavily quantitative questionnaires, and phenomenological interviewing. It demonstrates the potential of utilising a preliminary methodological stage to orientate the phenomenon (Van Manen, 1990) in order to ascertain a credible focus. This study proves the value of the preliminary stage in a predominantly qualitative study, thereby providing a justification for future studies to adopt a similar methodological approach.

Demonstrates a unique way to present sequential mixed-methods research

As noted above, this study made a unique contribution to the field of mixed-methods by using the preliminary stage one findings to orientate the phenomenological focus of stage two. Therefore, stage two was not designed until stage one had been completed and analysed. It seemed inappropriate to present the methodology and results sections in a traditional manner because it would be confusing to the reader to discuss a methodological approach prior to the presentation of results on which it was based. Therefore, this study adopted a pragmatic approach to presentation that reflected the emergent nature of the mixed-methods study. This involved presenting the stage one methods chapter followed by the results of stage one, which were then used to help present the stage two methods chapter. This unique way of presenting the data provides a more coherent template for presenting mixed-methods studies that are structured in this unique manner.

Promoting mixed-methods through discussion and dissemination

The final means by which this study has contributed to the field of mixed-methods research is through the promotion and presentation of the developed model of research by way of conversations with other academics, national and international conference presentations and, further down the line, through journal publications.

Whilst developing and utilising this methodological design, I was able to engage in numerous academic discussions regarding the methodological approach. Interestingly, on speaking to a number of researchers with qualitative or quantitative orientations, I discovered that many were under the illusion that mixed-methods research was entirely synonymous with the concept of cross-validation, in their opinion showing a lack of concern for paradigmatic differences between qualitative and quantitative research. It was refreshing to discover that many of these researchers were more willing to accept the current study in terms of its philosophical implications for research. An additional way that I promoted this approach to mixed-methods research was through discussions at both national and international conference level. Specifically, I was lucky enough to share my model with other mixed-methods researchers at a conference designed specifically for researchers conducting this form of research. In addition, I also discussed my ideas with regards to mixing at a qualitative research conference, where the presentation was very well received. I intend to publish my reflective findings about conducting mixed-methods research as well as details about the previously discussed model in order to provide assistance to others hoping to conduct mixed-methods research in the future. This will help to continue the contribution that this study makes to the field of mixed-methods research.

Reflection: The Methodological Challenges

The above discussion demonstrates that the methodological choices adopted by the current study made a unique and rich contribution to the value of the study as well as to the field of research methods in terms of mixed-methods research. However, conducting a mixed-methods study also raised numerous challenges and obstacles that needed to be overcome. These challenges included ensuring that the study's methodological defence was clearly maintained, as well as dealing with time constraints and issues that arose from using multiple forms of research. In addition to these obstacles, I encountered a significantly higher number of objections from others compared with what I had experienced in the past when conducting qualitative and quantitative research, and these had to be dealt with accordingly. The following will elaborate on these methodological challenges and provide details about how they were surmounted as part of the research project.

Establishing and maintaining a consistently clear methodological position

The knowledge gained through conducting this research project has helped me recognise that, in order to develop a mixed-methods research project of discernable quality, it is important to be consistently clear about the methodological stance in terms of philosophical standpoint and mixing strategies. As the methodological design was arguably more complex than a study operating within a single paradigm, it is vital to outline the philosophical position in terms of the methodology prior to designing the study, and to be explicit and consistent about this decision throughout the presentation in order to effectively communicate the methodological underpinnings of the research. In addition, one of the key criticisms of mixed-methods research is a lack of clarity regarding the integration of qualitative and quantitative findings (Creswell and Tashakkori, 2007). If I had not been clear about my use of reformed notions of complementarity as a motivation for mixing, or of the combination within the discussion to provide a more complete picture of the research area, it would have been easy to alienate potential audiences and leave the research open to unnecessary scrutiny. Although it is vital to make explicit the philosophical position of the researcher within traditional, single-method qualitative and quantitative research, the additional philosophical and paradigmatic debate associated with mixing methods adds to the importance and challenges associated with this task. I overcame these obstacles by returning to the mixed-methods literature at various points throughout the study and outlining my philosophical position prior to the design of the methodological structure. Similarly, in order to clarify the methodological stance of the study, the strategy for mixing and combination was also made explicit prior to the research being undertaken.

Dealing with inherent time constraints

One of the main barriers to conducting mixed-methods research is the time constraints that are incurred by combining multiple methods within a single study. Specifically, I found that the sequential nature of the design of the current study amplified this issue even further. This study involved conducting two individual participant recruitment drives, designing two data collection methods (questionnaires and interview structure), engaging in two separate forms of data analysis, and seeking a more complex form of ethical approval than would be required by most single stage studies. Needless to say, these additional tasks elongated the research process considerably

and incurred additional time challenges that needed to be faced accordingly. It could be argued that similar challenges might be faced within longitudinal or multiple-stage single-method studies. However, the additional consideration that has to be paid to integration and philosophical stance (as discussed earlier) that accompanies the decision to conduct mixed-methods research implies additional time constraints than those posed by single-method studies. The complexity of the research process and the time-consuming nature of the structure of the research could be viewed as one of the key limitations to the study. However, these restrictions could not be prevented because combining these stages would have had implications for methodological adequacy. Therefore, the only way to overcome these challenges was by effective planning and structured working. I was aware of the potential issues involved with conducting a sequential mixed-methods research project within a three-year period so, in response, I planned the stages and participant numbers accordingly and allowed for additional time when required. Thankfully, the study was conducted within the deadlines imposed during planning, thereby adequately dealing with the issue.

Moving between different methodologies

A further complication that needed to be addressed in terms of the chosen methodology was the difficulty in moving between a predominantly quantitative, highly numerical and statistical approach to another with its roots in the linguistic practice of descriptive phenomenology. This is far more of a challenge when conducting entirely concurrent mixed-methods studies where the two research methods must be performed side by side. By keeping the design sequential, it was easier to maintain the philosophical underpinnings of reformed notions of complementarity. The sequential design also had a positive effect on my ability to effectively cope with the challenge of moving between two different research methods. The qualitative data within stage one was analysed completely separately to the quantitative data and was combined at the point presentation. The main challenge came with moving from conducting a highly quantitative stage one to the phenomenological second phase. In order to surmount this challenge effectively I immersed myself in the phenomenological literature prior to commencing this stage of the study, which helped me considerably to refocus.

It is commonplace within mixed-methods studies to build teams of researchers who offer different specialties in terms of research methods. This, however, is not a practical solution for a PhD study. I therefore had to build on my existing research skills in order to conduct both qualitative and quantitative forms of analysis. Although this involved a lot more work, I feel that it has benefitted the study in terms of cohesion as I was able to effectively use the information from stage one to inform stage two, without having to communicate my findings to another person which may have led to confusion. In addition, it allowed me to develop my skills as a researcher, and improved my confidence in using different data collection, interpretation and analysis techniques.

Presentation

As previously noted earlier within this chapter, one of the potential benefits of conducting mixed-methods research is the opportunity it offers in terms of flexibility of the presentation and dissemination of findings. The use of multiple methodological approaches allows the researcher the potential freedom to tailor the language of the presentation to suit each audience without compromising the findings or cohesion of the study. However, this advantage of conducting mixed-methods research also presents additional challenges in terms of supplementary decisions that need to be made regarding this, as well as decisions about the basic presentation of mixed-methods findings. Arguably the most imperative criterion for evaluating the success of research projects is the researcher's ability to effectively communicate the merits of their findings to an audience (Sandelowski, 2003). In terms of mixed-methods research, the challenge of this task is amplified as researchers from different paradigmatic stances often have very different ideas about what is appropriate and successful in terms of the presentation of findings. This challenge was overcome in the current study by primarily providing an explicit philosophical argument for mixing and justifying methodological decisions in order to aid general understanding about why the research was presented in such a manner. In addition, despite the sequential nature of the study, a relatively consistent overall tone was applied to the presentation which did not delve too deeply into language specifically associated with either side of the paradigmatic debate. Put simply, this study is a mixed-methods research project and, therefore, instead of adopting excessively qualitative and quantitative language depending on the stage, the research was presented in a more

neutral fashion in order to improve accessibility. Of course, so as not to compromise the methodological quality, there were times when a different tone was required. In these instances, a justification was made prior to the change in presentational style to include the potential audience in the methodological process.

Overcoming objections

The final challenge that was faced came in the form of the objectionable opinions and responses that I encountered from qualitative and quantitative researchers to the knowledge that I was conducting a study that combined methods from different paradigms. As well as numerous positive responses to my methodological choices, over the past three years I have also encountered negative opinions towards mixed-methods research from fellow researchers during graduate training sessions, conferences and general discussions. In an attempt to overcome these objections, I have readily engaged in academic debates relating to my methodological choices and have defended my reasoning. In addition, I have taken the further action of presenting my experience of objections at a qualitative research conference where I drew parallels between the plight of the mixed-methods researcher and that of the qualitative researcher 30 years ago engaged in the paradigms debate to raise awareness. I also justified my methodological choices in this arena, which allowed me to test my methodological argument and enlighten fellow researchers to the range of motivations for combining methods.

In summation, conducting a mixed-methods research project has meant refining my philosophical standpoint, improving my skills within research methodologies, and has presented me with numerous time-consuming obstacles in terms of combination and presentation. However, despite these difficulties, the adoption of a mixed-methods approach has allowed me to achieve relevance within the overall focus of the study and a more comprehensive discussion of the overarching phenomenon. Although I had concerns prior to conducting this study because it was my first experience of conducting mixed-methods research, on reflection there is no possibility that I could have produced such relevant and inclusive findings from a single-method study.

Chapter 11. Conclusion

Over the past two decades, the internet has become an important medium for the public seeking health information and health services online. Recently published internet usage statistics have identified a dramatic rise in the number of people within the United Kingdom (UK) using the internet to locate online health information (OHI) (Office of National Statistics, 2007, Office of National Statistics, 2008, Office of National Statistics, 2009). As more people turn to the internet for health information, the number of health-related websites and online tools has increased dramatically to cope with the demand, leading to a proliferation in creation and distribution of OHI (Oermann et al., 2003, Sillence et al., 2007). Despite the increasing popularity of the internet as a source of health information, relatively little research has considered how individuals are operating as OHI seekers. Currently, in order to provide a discussion of how patients may be operating within this role, it is necessary to turn to the United States (US) (Pew Internet, 2000, Fox, 2001, Fox and Rainie, 2002, Pew Internet, 2003, Harris Interactive, 2008, Pew Internet, 2009) hailing the need for additional research into the way that these individuals operate within the UK, and the potential benefits of OHI seeking for the general public.

A review of the literature demonstrated that, although there is limited research available regarding how people look for health information online, the relatively rare studies have suggested that engaging with OHI has many potential benefits for patients. These proposed benefits include supplying a wealth of health information that could be tailored to an individual's personal health needs (Cline and Haynes, 2001) and the potential for OHI to reach people living in remote areas and underserved populations (US Department of Health and Human Services, 2002, Becker, 2004). Furthermore, the literature review also demonstrated that OHI could potentially empower patients in addition to promoting self-care and patient choice. However, despite these potential benefits of OHI, the literature has also outlined numerous barriers that have the capability to stand in the way of patients locating useful and relevant OHI. The key barriers identified by the literature are information quality (Mandl et al., 2001), patients' search and appraisal skills (Eysenbach and Kohler, 2002), literacy levels (Cline and Haynes, 2001) and demographic factors such as age, education and race (Brodie et al., 2000). Furthermore, previous research demonstrated the potentially important role that others play in individuals' OHI-

seeking experiences. Health professionals in particular are paramount in facilitating the emergence of information-enabled patients by moving forward from the traditional paternalistic model of health care to one of partnership (Coulter, 1999).

This literature review formed the background for the current study. Stage one utilised two predominantly quantitative questionnaires in order to gather broad data relating to the experiences of OHI seeking for adults with chronic health conditions, and the barriers to OHI as perceived by non-users. The findings from this stage were utilised to inform the focus of the second, qualitative stage of the study. Stage two used in-depth phenomenological interviews to explore, in a detailed way, how searching for health-related information online became a meaningful activity for older adults living with chronic health conditions.

The rest of this chapter will continue to focus on concisely reporting the findings of the study in relation to the research aims, and on summarising the implications of these findings.

Achieving the Study's Aims & Objectives

The study had four key aims that were identified prior to the research plan being developed. The first of these aims was to contribute to the field of consumer health informatics in terms of providing a depth of information relating to the OHI-seeking experience. The second aim was to use this depth of information to develop a focused experiential study that would produce information relating to the OHI-seeking experience with an appropriate phenomenological focus. The third aim was to make a unique and innovative contribution to the field of mixed methods. The final aim of the study was to make a contribution to knowledge that could help inform the training of health professionals in the future.

Breadth

The stage one questionnaires provided a breadth of both quantitative and qualitative data that contributed to the overall understanding of the nature of the OHI-seeking experience for older adults with chronic health conditions. Primarily, quantitative data demonstrated that, although a lower percentage of respondents had used the internet in the current study compared with a recent national survey (Office of National

Statistics, 2009), OHI usage for internet users was much higher in the current study. It was hypothesised that this effect was due to the fact that only patients with chronic health conditions were included in the sample.

Further statistical analysis demonstrated that, in line with the early literature (Brodie et al., 2000), high age and low education levels were barriers to OHI. The current study also demonstrated, perhaps unsurprisingly, that low internet usage levels acted as a further barrier. These three variables also had an effect on the outcomes of OHI seeking generally. Older, less educated and more infrequent internet users were less likely to perceive the positive effects of OHI seeking, such as gaining confidence in discussions with health professionals and making healthcare decisions. The stage one data also demonstrated that, in terms of age, a number of non-usage participants felt that they were “too old” to use the internet. This finding was in line with previous literature that noted similar statements from older adults (Gustafson et al., 1998, Stanley, 2003, Turner et al., 2007).

The stage one data also demonstrated that respondents located OHI through various means, such as referrals and search engines, and overwhelmingly agreed that it was easy to find OHI. Despite this, the majority still felt that the quality of OHI needed to improve. This finding conflicts with a recent US survey that was far more positive in terms of the respondents’ perceptions of OHI (Harris Interactive, 2008). When asked if they felt confident assessing quality, just over half of participants within the current study agreed with this statement. The qualitative stage one data complemented this finding by outlining that patients wanted assistance from health professionals in order to help them locate high quality OHI. In addition, both OHI users and non-users demonstrated that health professionals were the most important source of health information for them, suggesting that OHI seekers were not substituting the professional’s knowledge with OHI. The final surprising key finding in terms of breadth was that a number of participants who completed the non-usage questionnaire were unaware that OHI existed. This finding demonstrates the scale of the digital divide in terms of knowledge and understanding of OHI.

Depth

The second aim was to produce a depth of experiential data relating to the OHI-seeking experience for adults with chronic health conditions. The stage one findings demonstrated that the experience of older adults with chronic health conditions seeking OHI would be an appropriate phenomenological focus for stage two of the study. The phenomenological analysis of the in-depth interviews uncovered five key findings that helped describe the nature of OHI-seeking experiences generally.

The first key theme that was identified was 'Responsibility'. The stage two data illustrated that the OHI-seeking experience for older adults was an explicit demonstration of an individual's intention to take control of their health or the health of a loved one. This responsibility was taken almost automatically and without justification, demonstrating a perceived sense of bodily ownership, which is in line with previous literature (Spiers, 1997). Furthermore, the lived experiences demonstrated that participants had an intention to share responsibility with professionals and engage in a partnership relationship in line with UK health policy (NHS Executive, 1996, Coulter, 1999) and stage one data, which illustrates the important role that health professionals play in the lives of OHI seekers.

The second key theme of the data was patient 'Expectations'. Patients demonstrated that they had a specific set of expectations regarding OHI which, when fulfilled, led to the patients perceiving the experience as positive. This finding concurs with the previous literature that demonstrated a specific link between the fulfilment of patient expectations and feelings of satisfaction (Linder-Pelz, 1982, Zyzanski and Like, 1987, Sitza and Wood, 1998, Kravitz, 2001). Patients specifically showed that they had different forms of expectations: general expectations, formed from long-term experience and unconsciously ingrained within their minds, and query-specific expectations, which were short term and based on their specific needs at that precise moment.

The third key theme was 'Confidence and concern'. Although only just over half of the participants demonstrated confidence in their ability to discern OHI quality within the stage one usage questionnaire, older adults in stage two illustrated that confidence in their ability to discern was a key feature of the OHI-seeking experience. It was

hypothesised that this difference was due to the second stage of the study attracting more confident internet users. Interestingly, a further feature of the OHI-seeking experience for older adults was a concern for others to do the same. The experiences demonstrated a sense of awareness and immunity. This finding potentially has implications for the quality debate that has existed for a number of years within the field of consumer health informatics (Cline and Haynes, 2001, Eysenbach et al., 2002).

The next key theme related to the nature of sharing within the OHI-seeking experience and was termed 'Selective sharing'. This theme demonstrated the huge social element of the OHI-seeking experience for older adults with chronic health conditions as predicted by previous literature (Pew Internet, 2009), and showed that participants were engaging in sharing with family, friends, peers from other support groups and health professionals. The lived experiences illustrated that a unifying attribute of the OHI sharing experience was that in all cases it exclusively followed a positive seeking experience. The experiential data therefore suggested that older support group members engaged in a form of offline peer review in order to ensure only potentially beneficial OHI was passed through information sharing networks. This behaviour demonstrates that, although patients revealed a desire to include health professionals in the process of reviewing OHI, they were also able to rely on peers to ensure that they located high quality, relevant information. The lived experiences also demonstrated that sharing quality information was an important feature of support groups in the minds of these respondents, in line with previous research (Robinson, 1988).

The final key theme in terms of the experience of older adults with chronic health conditions seeking OHI was 'Reactions and reinforcement'. Although stage one data reported that respondents encountered perceiving mixed reactions when they shared with friends, family and support group peers, the lived experiences identified that participants experienced overwhelmingly positive reactions from others as part of the OHI sharing experience. These positive reactions reinforced the sharing behaviour, leading to the development of a social sharing network where quality OHI could be distributed freely. However, in line with stage one findings, the lived experiences demonstrated that reactions from health professionals were inconsistent. The negative

reactions from health professionals had the opposite effect and inhibited the development of a forum in which information could be freely shared, thereby potentially inhibiting the emergence of a partnership between patient and professional.

Methodological contribution

As specified within the study's aims and objectives, in addition to providing a breadth and depth of information relating to the nature of OHI seeking as experienced by adults with chronic health conditions, a further aim of the study was to review and develop innovative mixed-methods research techniques in order to make an original contribution to the field of research methods. Specifically, the current study made a contribution to the field of mixed-methods in five key ways. Firstly, the study contributed by providing a philosophically sound example of mixed-methods research that respected the epistemological differences between qualitative and quantitative approaches. Secondly, this study had a unique input into the field by identifying the opportunities for pragmatism in mixed-methods research through designing a methodology that met the aims of the research as opposed to fitting the aims and design of the study around researcher preferences or bias. The third way in which this study contributed to mixed-methods research was by demonstrating a new template for mixed-methods research design that combined qualitative and quantitative concurrent data collection with a subsequent and predominantly qualitative stage. This model allowed for the consideration of an appropriate qualitative focus for stage two based on the findings, and helped develop a more holistic discussion of the overall phenomenon. This research project made a fourth contribution to mixed-methods research by demonstrating a unique way of presenting data to reflect the sequential nature of mixed-methods research and the emergent experiential focus. Finally, the current study made a unique contribution to the field by promoting the model and methodological findings through general discussion and dissemination.

Contribution to knowledge

The final aim of the study was to make a significant contribution to the field of consumer health informatics. This study made a contribution by providing and developing knowledge in five key areas. Primarily, the research developed the understanding of older adults and the OHI-seeking experience by providing

experiential examples. These lived experiences gave explicit evidence that older adults were able to engage in the OHI-seeking experience successfully, thereby contradicting the perceived opinion that they may be “too old” to take part in such activities, as was expressed by participants within stage one and in the former literature (Gustafson et al., 1998, Stanley, 2003, Turner et al., 2007). The research also made a contribution to knowledge by confirming the previous findings that patients wished to take varying levels of responsibility for their health (Henwood et al., 2003). The study also added to existing research in terms of the ongoing quality debate in consumer health informatics (Eysenbach et al., 2002) by illustrating that patients had an awareness of poor quality OHI. Specifically, stage one data demonstrated that over half of participants had confidence in their ability to discern OHI quality. Furthermore, the study contributed by demonstrating that health professionals were the most important source of OHI information for both OHI seekers and non-seekers. Finally, the study made a contribution to the field of consumer health informatics by confirming and describing the social nature of the OHI-seeking experience, in terms of the role of health professionals and others such as friends, family and support group peers.

Implications of Findings

The study illustrated a number of implications for practice based on the discussion of key findings. The first key implication for practice was that health professionals should become involved in their patients’ OHI-seeking processes by providing them with support and referrals. Findings also demonstrated the importance of health professionals understanding patient preferences in order to engage in effective partnership relationships. Furthermore, the stage two findings have implications for practice in terms of their potential to help professionals understand their patients’ experiences. The lived experiences specifically demonstrated a need for professionals to understand patients’ bodily responsibility and expectations, and the important role they play in reinforcing the partnership relationship with patients.

The study also identified four key areas for future study based on the unique contribution to knowledge. These were in terms of understanding patient preferences; the effect of OHI usage on health service utilisation; naturalistic observation of participants’ assessments of OHI quality; and the effect on the patient’s overall

seeking experience of practitioner referral to OHI or OHI information leaflets provided during consultations.

This study has highlighted the need for further research into the field of consumer health informatics within the UK, specifically in terms of how individuals use OHI and the impact this has on their ability to self-manage chronic health conditions. The study has also provided rich data with the potential to inform both practice and further study, and has made a unique contribution to the field of mixed-methods research. On reflection, this research project has also enabled me to develop my philosophical views on the research process and the utilisation of methodological approaches, and has installed in me a desire to conduct further studies that have practical implications in terms of improving the wellbeing of individuals with chronic health conditions. My insight tells me that this thesis is the first step on a long and exciting road of discovery.

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Questionnaire

How people use the internet to look for health information

Please complete the following questions fully. Please note that where the term **'health professional'** is used, this refers to any professional who helps in identifying or preventing or treating illness or disability e.g. G.P, Nurse, pharmacist, physiotherapist.

1. How often do you use the internet? (Tick one)

- 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
- Not at all in the last three months

2. Apart from to seek health information, what do you use the internet for? (Tick one main, and as many additional sources as apply)

	Main	Additional
Email		
Web Surfing		
Work		
Education		
Online Chat		
Online Shopping		
Online Games		
Social networking		
Other (please specify _____)		

3. Approximately how often do you use the internet to seek health information about your condition? (Tick one)

- More than once a week
- Weekly
- Monthly
- Every 3 months
- Every 6 months
- Less than every 6 months

4. Does the amount that you use the internet to seek health information vary? (Tick one)

Yes

No

4.b If yes, please indicate which factors make you use the internet to seek health information more/less?

5. What are your reasons for seeking health information online? (Tick one main, and as many additional reasons as apply)

	Main	Additional
To understand what's wrong		
To support myself		
To help support others		
To prepare for a consultation with a health care professional		
To understand what was discussed in a consultation with a health care professional		
To understand the outcomes of tests/treatment		
To help self-manage my condition		
To overcome concerns		
For information on support groups		
For information on healthcare providers		
Other (Please specify) _____		

6. What do you feel is the most important source of health information for you? (Tick **one main**, and **as many additional** sources as apply)

Sources	Main	Additional
Health professionals		
Internet/website		
Leaflets		
Books		
Family and friends		
Newspapers or magazines		
Pharmacist		
Patient organisations		
Television or radio		
Other (Please specify) _____		

7. To what extent do you agree with the following statement- 'It's easy to find useful and relevant health information on the internet' (Tick one)

Strongly Agree

Agree

Neither Agree/Disagree

Disagree

Strongly Disagree

Additional comments

8. Do you ever use search engines to find health information online? (Tick one)

Yes No

8.b If Yes, which ones have you used?

9 Have you ever been referred to online health information? (Tick one)

Yes No

9.b If So who was it by? (Tick all that apply)

- Health professional
 - Family/friends
 - Members of a support group
 - Other
- (If other, please specify)

10. What do you think might help you be more able to locate health information online?

11. To what extent do you agree with the following statement- 'The quality of health information on the internet needs to improve' (Tick One)

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Additional Comments

12. Do you feel that you are able to accurately asses the quality of online health information? (Tick One)

- Yes No

13. What factors do you consider when assessing website quality?

14. What do you feel would increase your ability assess the quality of online information?

15. What do you do with online health information once you have found it?
(Tick all that apply):

- Read it online
- Save it to my computer
- Print it off for my personal use
- Print it off to show others
- Other

(If other, please specify)

16. If you do print it off to show others, who do you show it to?

17. In your experience, how have people reacted when you show them health information that you have found online?

18. To what extent do you agree with the following statement- 'Bringing online information with me, improves my consultations with health professionals' (Tick One):

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Additional Comments

19. To what extent do you agree with the following statement- 'in my experience, health professionals react positively to me bringing online information into the consultation' (Tick One)

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Why is this?

20. Does seeking health information online make you feel more confident to make decisions about your healthcare? (Tick one)

Yes No

20b. Why is this?

21. Does seeking online health information make you more confident about discussing your health and treatment regime with health professionals?

(Tick one)

Yes No

22. Has the information that you have found on the internet assisted in you making decisions about...(Tick all that apply)

Finding the best health care providers
 Choosing medication/treatments
 Joining support groups
 Other

(If other, please specify)

23. Please indicate which of the following conditions you have been diagnosed with (Please circle all conditions that apply)

Diabetes type 1	Diabetes type 2	High Cholesterol
High Blood Pressure	Heart Disease	Lung disease
Eating Disorder	Multiple Sclerosis	Blood Disease
Muscular Dystrophy	Stroke	Cancer
Arthritis	Other (Please Specify)	

24. Please indicate the approximate length of time in years and months since you were diagnosed (If you have been diagnosed with more than one, please use the most recent).

25. In General, would you say your health is (Tick one):

- Excellent
- Very Good
- Good
- Fair
- Poor

26. Have you ever been involved in an NHS Expert Patient Programme?

- Yes No

27. Have you ever been involved in any other illness self management programme?

- Yes No

27b. If so, please give details:

28. Gender (please tick appropriate)

- Male Female

29. Age (years) _____

30. Please indicate your highest educational qualification

Thank you for taking the time to complete this questionnaire. Please ensure that all questions have been answered completely and accurately

Questionnaire**Why people aren't using the internet to look for health information**

Please complete the following questions fully.

Please note that where the term '**health professional**' is used this refers to any professional who helps in identifying or preventing or treating illness or disability e.g. G.P, Nurse, pharmacist, physiotherapist.

1. Have you ever used the internet?

Yes (Please go to question 3)

No (Please go to question 2)

2. Why have you never used the internet? (Then skip to Question 7)

3. How often do you use the internet? (Tick one)

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

Not at all in the last three months

4. What do you use the internet for? (Tick one main, and as many additional sources as apply)

	Main	Additional
Email		
Web Surfing		
Work		
Education		
Online Chat		
Online Shopping		
Online Games		
Social networking		
Other (please specify _____ _____		

5. Why don't you use the internet to access online health information?

6. What would make you more likely to use the internet to access online health information?

7. What do you feel is the most important source of health information for you? (Tick one main, and as many additional sources as apply)

Sources	Main	Additional
Health professionals		
Leaflets		
Books		
Family and friends		
Newspapers or magazines		
Pharmacist		
Patient organisations		
Television or radio		
Other (Please specify)		

8. Please indicate which of the following conditions you have been diagnosed with (Please circle all conditions that apply)

Diabetes type 1	Diabetes type 2	High Cholesterol
High Blood Pressure	Heart Disease	Lung disease
Eating Disorder	Multiple Sclerosis	Blood Disease
Muscular Dystrophy	Stroke	Cancer
Arthritis	Other (Please Specify)	

9. Please indicate the approximate length of time in years and months since you were diagnosed (If you have been diagnosed with more than one, please use the most recent).

10. In General, would you say your health is (Tick one):

- Excellent
- Very Good
- Good
- Fair
- Poor

11. Have you ever been involved in an NHS Expert Patient Programme?

- Yes No

12. Have you ever been involved in any other illness self management programme?

- Yes No

12b. If so, please give details:

13. Gender (please tick appropriate)

- Male Female

14. Age (years) _____

15. Please indicate your highest educational qualification

Thank you for taking the time to complete this questionnaire. Please ensure that all questions have been answered completely and accurately.



**Research Governance Review Group
Review Report (staff researcher PhD study)**

Researcher(s) **Joanne Mayoh**

Supervisors; **Dr. Carol Bond; Professor Les Todres**

Title: **Navigating the maze of online health information: the experience of people with chronic health conditions**

Reviewers: 1 senior academic

Report prepared by: Martin Hind (RG2 co-ordinator on behalf of the School Research Committee)

Date: 7.4.08

Dear Joanne

Thank you for submitting your research proposal for review. This was a very comprehensive submission that included all relevant documentation. The quality of your submission is to be commended.

Your proposal articulates very well your intended methodology and in particular the participant information sheets were very clearly written and most appropriate for the intended participants.

However, it was difficult to assess if your intended timescales were realistic as no calendar was presented and you are advised to liaise with your supervision team in respect of this.

Regarding NHS REC approval, your argument that recruitment through support groups may negate the need for NHS REC approval, is noted, but given that your intended participants are not

'healthy volunteers' you are advised to consider checking with your local NHS REC for specific advice on this matter.

Thank you for taking the time to submit a very competent proposal.

Please do not hesitate to contact Martin Hind at rg2@bournemouth.ac.uk if you have any queries, or need further clarification in relation to the feedback on your proposal.

Candidate Information Sheet

I would like to invite you to participate in my research project on the experiences of patients with chronic illness using the internet to make choices about their health and treatment regimes. Before you make a decision, it is important for you to understand why the research is being done, and what it will involve. Please take your time to read the following information carefully. Do not hesitate to talk about the study with other people.

Who am I?

My name is Joanne Mayoh and I am a PhD student at Bournemouth University. My supervisors are a Professor and a senior Lecturer in the school of Health and Social Care. The research has been assessed by the School Research Ethics Committee and is entirely funded by Bournemouth University.

Why am I doing this research?

The Department of health (DoH) are currently developing policies centred around what they call patient-led care. This is because it is the governments' belief that involving chronically ill patients in making their own health care decisions will result in a greater sense of empowerment and control for patients. The DoH suggests that the best way for patients to become involved in their healthcare decisions is to encourage them to actively seek out information about their conditions from the internet, and other electronic sources such as NHS Direct on Digital T.V. This research will be looking at the experiences of people like you of using of the internet in making choices about their health and treatment. Although there have been some studies on the use of internet and electronic health information, the volume of data collected does not represent the rapid growth of the phenomena. By developing our general understanding of how patients use this information, we can make valid recommendations about what goes in to primary carers (G.P's and nurses) education in order to help people with chronic illness receive the help and assistance that they need in the future.

Who can take part?

I am inviting people over the age of 18 who have been diagnosed with an ongoing chronic illness to participate. My sample area will be the South Coast of England, and I'm aiming to use this questionnaire on between 100 and 150 participants.

What would be involved?

I would like you to take part in my questionnaire, which is completed anonymously and should take around 20 minutes.

What will I do with the information?

The information will be used as data for my PhD thesis which will be assessed in order for me to gain the PhD degree. The data from all participants will be brought together and may be used to write and publish articles in academic journals. You are welcome to see an executive summary of the final project, and

on request, I will be able to provide details of where you can access copies of the thesis, and papers once they are available online.

Will the information from the questionnaire be kept private?

The information will be stored in locked filing cabinets within the university, and will only be used by myself and my supervisors. No names or individual data will be used within the final thesis.

What if you change your mind about taking part?

Your decision to take part in this study is entirely voluntary, and if at any point you decide to withdraw from the study, you may do so with no explanation needed. If you wish to make any comments or complaints about the project, or my performance please contact Dr Carol Bond (details below).

Joanne Mayoh

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	01202 962730/ 07795006425

Dear xxx,

I am writing to introduce myself as a current Bournemouth University PhD student who is conducting research into chronic illness. I have found the details for your support group online, and subsequently I am very interested in inviting the members of the group to participate in my research project.

Specifically, my research will look into how people with chronic illness use the internet as part of their health and treatment regimes. My project will be conducted under the supervision of Dr Carol Bond and Prof. Les Todres of the school of Health and Social Care at Bournemouth University.

I would like to invite the members of your support group to participate in the first stage of my investigation by conducting a short multiple choice questionnaire which will look at how they use the internet and electronic information to search for health information, and what they do with this information once they have found it. Ideally I would like to attend a support group meeting and give a quick talk outlining the research, and then give the members the option to take part in the study. It is hoped that the findings from this study will help contribute to a better understanding of how people with chronic illness support their information needs, and help make recommendations about what should be included in healthcare professionals' education as a result.

I would really appreciate your consideration on this matter, and would be pleased to hear any feedback, or answer any questions that you may have regarding my research. I can be contacted by phone, post or email using the details listed above.

Yours Sincerely,

Joanne Mayoh
PhD Student
Bournemouth University

From: Research Governance Review Queries
Sent: 28 October 2009 11:45
To: Joanne Mayoh
Cc: Eva Papadopoulou
Subject: FW: Ethics

Dear Joanne

Thank you for your enquiry

Your amendment is the place of the interviews and as such the original approval conditions (ie recruitment to participate and consent to interview) remains the same and therefore you are still RG2 approved to conduct these interviews in the revised setting.

This amendment will be ratified at the HSC Postgraduate Committee on 11th November 09 but please take this email as evidence to proceed with your amendment.

Thanks for taking the time to inform us.

with very best wishes

Martin Hind (RG2 coordinator)

Appendix G

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Xx/xx/xxx

Joanne Mayoh
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01202 962730/ 07795006425

Dear xxxxxxxx,

Thank you ever so much for allowing me to become involved with your support group and letting me offer the members the chance to complete my questionnaire into the usage of health information. I am pleased to report that the response rate was really high within the group and from this I have taken some interesting data which has contributed to some quality results for the first stage of my PhD.

I am now at the stage that I am offering to present the findings from the first stage of the PhD to the support groups who took part so that they can be the first people to hear about the findings from the questionnaires, and understand how their efforts have contributed. It will also give me the opportunity to explain how the data will be utilised moving forward and invite people to become more involved within the second stage of the study if they so wish.

I am proposing that, if you have any availability, I could attend a support group meeting between now and the end of November 2009 and present my findings. This could consist of a quick 15 minute chat or a full blown lengthy presentation, whichever you feel would be more appropriate and will fit in with your schedule.

I understand that you are busy, but I would really appreciate any time that you could give me to thank those who took part and to let them know how their efforts will be utilised moving forward. Please feel free to contact me using the details above to discuss this proposal in more detail,

Yours Sincerely,

Joanne Mayoh
PhD Student
Bournemouth University

Navigating the maze of online health information: the experiences of people with chronic health conditions

Participant Information Sheet: Individual Interviews

I would like to invite you to participate in this stage of my PhD research project on the experiences of older adults using the internet to seek health information. Before you make a decision, it is important for you to understand why the research is being done, and what it will involve. Please take your time to read the following information carefully. Do not hesitate to talk about the study with other people.

Who can take part?

Participants must:

- Attend a support group involved in stage one of the study.
- Be over 60 years old.
- Have been diagnosed with an ongoing chronic health condition.
- Be prepared to describe their experiences in health information seeking on the internet.

Who am I?

My name is Joanne Mayoh and I am a PhD student at Bournemouth University. My supervisors are a Professor and a Senior Lecturer in the school of Health and Social Care. The research has been assessed by the School Research Ethics Committee and is entirely funded by Bournemouth University.

Why am I doing this research?

The Department of health (DoH) are currently developing policies centred around what they call patient-led care. This is because it is the governments' belief that involving chronically ill patients in making their own health care decisions will result in a greater sense of empowerment and control for patients. The DoH suggests that the best way for patients to become involved in their healthcare decisions is to encourage them to actively seek out information about their conditions from the internet, and other electronic sources such as NHS Direct on Digital T.V. This stage of the research will be looking at the experiences of older adults using of the internet in making choices about their health and treatment. Although there have been some studies on the use of internet and electronic health information, the volume of data collected does not represent the rapid growth of the phenomena. By developing our general understanding of how older adults use this information, we can make valid recommendations

about what goes in to primary carers (G.P's and nurses) education in order to help older adults with chronic illness receive the help and assistance that they need in the future.

What would be involved?

I would like you to take part in a single interview which will last around one- two hours about your experiences as an older adult searching for health information over the internet. The interview will be recorded so that I can use it as reference in proceeding with the study. The interview will take place at the Lansdowne Bournemouth University campus, and your travel expenses to and from the venue will be paid.

What will I do with the information?

The information will be used as data for my PhD thesis, which will be assessed in order for me to gain the PhD degree. The data from all participants will be brought together and may be used to write and publish articles in academic journals. You are welcome to see an executive summary of the final project, and on request, I will be able to provide details of where you can access copies of the thesis, and papers once they are available online.

Will the information from the questionnaire be kept private?

The information will be stored in locked filing cabinets within the university, and will only be used by myself and my supervisors. No names or individual data will be used within the final thesis, and your input will be anonymous.

What if you change your mind about taking part?

Your decision to take part in this study is entirely voluntary, and if at any point you decide to withdraw from the study, you may do so with no explanation needed.

Who do I contact if I have a complaint?

If you wish to give feedback or have a complaint to make about me as a researcher, you are free to contact my PhD first supervisor Dr Carol Bond.

Joanne Mayoh/ Dr Carol Bond

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Informed Consent Form**Navigating the maze of online health information: the experience of people with chronic health conditions**

Joanne Mayoh

	Please initial
1. I confirm that I have read and understood the <i>Navigating the maze of online health information: the experience of people with chronic health conditions information sheet</i> . I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I give permission for this interview to be recorded on audio cassette.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	
4. I agree to take part in the study.	

Name of participant_____
Date_____
Signature

Example of Data Transformation Stage of Phenomenological Analysis

QU1) Experiences of looking for health information online

i)

1	Umm, well I had been suffering for a long from umm, mainly Fibromyalgia or Lichen Planus, and I got no satisfaction whatsoever really with the local people because they didn't seem to know about the Lichen Planus, and if you look in books there are only about 2 or 3 lines about it and, which were not at all helpful so I felt sure that there would be somewhere that I could look it up.	P3 had been suffering for a long time from mainly Fibromyalgia or Lichen Planus, and had no satisfaction whatsoever really with the local people because they didn't seem to know about the Lichen Planus. P3 found that if you look in books there are only about 2 or 3 lines about it which P3 did not find helpful, so P3 was sure that there was somewhere she could look it up.	P3 describes a situation where she had been suffering for a long time from two unrelated chronic health conditions (Fibromyalgia and Lichen Planus). P3 felt dissatisfied with the level of knowledge locally on one of the conditions (Lichen Planus) as well as the information in books, which she found limited. However, P3 remained sure that some information would be available elsewhere.
2	So they weren't very good, and I got into the internet and after a lot of getting all the wrong things and... also its quite difficult to get in actually because if you don't hit the right button you end up with worldwide medical umm, things, I found anyway, perhaps its just me umm and then you get stuck in other countries, and all I wanted to start with was the UK. And I missed the little bit that lets you, you know, hone in on the UK,	P3 felt they weren't very good and got into the internet, and got a lot of all the wrong things. P3 also states that it is quite difficult to get into because she felt if you didn't hit the right button you end up with worldwide medical things, P3 experienced this anyway and felt that it might just be her, and then P3 explained that she got stuck in other countries, and all P3 wanted to start with was the Uk. P3 believed she missed the little bit that lets you hone in on	P3 described feelings of dissatisfaction with the information, and explains that she went on the internet where she didn't initially get the right information either. P3 felt it was difficult because she believed that she missed the filter for national information and she was therefore confronted by international medical information. P3 described feeling unsure whether this was a unique or common experience.

		the UK.	
3	so I started again and got back to the UK, but I wasn't terribly umm, impressed	P3 states that she started again and got back to the UK, but wasn't terribly impressed.	P3 states that she repeated the process with the national filter, but explains that she felt unimpressed.
4	so I had another go because they did request umm that the United States had quite a lot of information so I got into, got into the USA and looked up first of all Fibromyalgia and Polymyalgia.	P3 states that she had another go because they did request that the United States had quite a lot of information, so P3 got into the USA and looked up first of all Fibromyalgia and Polymyalgia.	P3 states that she found out that another country had a lot of information (US), so P3 explains that she looked up the information from that country on the other condition (Polymyalgia) and a condition relating to that (Fibromyalgia).
5	Well there are pages and pages and pages, and it's quite ridiculous, most of it repeats two or three times.	P3 explains that there were pages and pages, and P3 found it to be quite ridiculous, with most of it repeating two or three times.	P3 describes that she felt overwhelmed with the volume of often repetitive information.
6	Fortunately I have quite a... I was a nurse for 40 years and I have quite a lot of medical knowledge so I was able to sort out what I thought was reasonable and, but referred to what I wanted to know, but it would be very difficult for somebody who knew nothing, I don't know how they manage. They probably get hold of the wrong things.	P3 explains that she was a nurse for 40 years and has quite a lot of medical knowledge so was able to sort out what she thought was reasonable and referred to what she needed to know. P3 states that she felt that it would be difficult for somebody who knew nothing, she explained she didn't know how they would manage and speculated that they may get hold of the wrong things.	P3 describes that she felt confidence in her ability to discern the reasonable and relevant information due to the medical knowledge she had gained during her career. P3 speculated that she had felt that it would be more difficult for someone if they didn't have medical knowledge to locate the right information.
7	So I just chose... I think I got about 10 sheets from there, and even then there is	P3 states that she got about 10 sheets from there, and even then she only found one	P3 stated that she got a number of sheets from that visit, however she

	only one sheet that really tells you something definite. The others are all, they waffle on about what you should be doing and what you shouldn't be doing which the majority of people cant do, and mention drugs, which, when I look them up some are available in this country, some are not. So that was that.	sheet that she believed told her something definite. She states that she felt that the others all waffle on about what people should be doing and what they shouldn't be doing, which she stated that she felt the majority of people couldn't do, and mention drugs which when P3 looked them up, she stated that she found out that some were available in this country and some where not. P3 stated so that was that.	personally felt that only one told her something definite. P3 speculated that the rest of the information was inappropriate for the majority of people and also explained that it discussed drugs some of which she believed were unavailable in this country.
8	So I then got on to the Lichen Planus where there was next to nothing apart from a short thing and I found out that India apparently (laughs) had a lot of Lichen Planus, I think because of eating curry or something, but its an inflammation of the mouth.	P3 states that she then got onto the Lichen Planus where there was next to nothing apart from a short thing, and she found out that India apparently has a lot of Lichen planus. P3 stated that she thought that this was because of eating curry or something and explained that it is an inflammation of the mouth.	P3 states that she then looked up the condition she initially had trouble finding information on (Lichen Planus) and only found a small amount of information. From this P3 then claims to have learnt that this condition was prevalent in another country, which she speculated may be to do with their diet.
9	And I found that there were lots and lots of addresses, and the people, I think mainly in Bombay seemed to be a centre for that, umm that was much better laid out on the whole, whether they have better people or whether they are more tuned into an individual thing.	P3 states that she found that there were lots and lots of addresses, and she felt that Bombay seemed to be a centre for that. She explained that she felt that that was much better laid out on the whole and she speculated whether they have better people or whether they are more tuned into an individual thing.	P3 states that she then found more comprehensive information from this other country where it was more prevalent including contact information and information with a superior layout.

The Experience Being Described	Experience Number & Author
Experiences of looking for health information online	i) Claire
	ii) Denise
	iii) Denise
	iv) Edward
	v) Edward
	vi) Edward
	vii) Edward
	viii) Edward
	ix) Edward
	x) Fiona
	xi) Fiona
1. Experiences of not being able to find health information online	i) Denise
	ii) Fiona
2. Experiences of finding poor quality health information online	i) Brian
	ii) Claire
	iii) Edward
	iv) Fiona
	v) Fiona
	vi) Fiona
3. Experiences of online health information helping one understand something better,	i) Brian
	ii) Claire
	iii) Denise
	iv) Edward
	v) Fiona
4. Experiences of online health information increasing ones confidence,	i) Brian
	ii) Claire
	iii) Denise
	iv) Edward
	v) Edward
5. Experiences of sharing online health information with a health professional,	i) Claire
	ii) Denise
	iii) Denise
	iv) Edward
	v) Fiona
6. Experiences of sharing online health information with friends, family or peers.	i) Amy
	ii) Brian
	iii) Denise
	iv) Denise
	v) Fiona
	vi) Fiona