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The use and integration of online  
information in health decision making

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PhD

2018

The use and integration of online  
information in health decision making

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The thesis is submitted in partial fulfilment  
of the requirements of the University of  
Northumbria at Newcastle for the degree of  
Doctor of Philosophy

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# Abstract

Online health information provides people with access to information, support and advice across a range of different health conditions. Although consumers and healthcare professionals (HCP's) acknowledge that people regard online health information as a key resource, a number of barriers prevent patients from disclosing and integrating the information into discussions with HCP's. Existing literature has focused almost exclusively on individuals with long term health conditions and has failed to consider how patients with short term conditions use online health information to support a broader range of health decisions including but not limited to treatment decisions. This thesis set out to specifically address these issues, by a) investigating how online health information is used to support a number of health related decisions across a range of short and long term health complaints, and b) whether intentions to integrate information into appointments with the HCP can be increased.

These two research questions were explored using a mixed methods approach across five studies. The research aimed to qualitatively explore how individuals with short term and long term health conditions use online health information to inform a broad range of health decisions, and examine how this information is integrated into appointments with HCP's. These findings were then confirmed quantitatively with a larger, more diverse sample. HCP's were then asked about their experiences of internet informed patients and the role that online resources can play in decision making. These findings were fed into the development of an experimental study that aimed to increase intentions to integrate online health information into appointments with HCP's

The thesis findings showed that online health information informed a number of different health decisions. Specifically, narrative information containing the experiences of others empowered participants to make decisions and increased satisfaction with health decision making. Findings also identified discordance between patients' perceptions of HCP's attitudes towards internet informed patients, and the HCP's actual views, which prevented participants from integrating online health information into their medical appointments. An experimental study aimed to increase patient intentions to discuss online health information with HCP's, by manipulating versions of narrative health information. Findings showed that narrative information when paired with either a self-reflection component or discussion starter component but not both, increased participants' intentions to discuss online health information with their HCP. The theoretical and practical implications of these findings are discussed alongside suggestions for future research.

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Finally, to my examiners, I hope you find this thesis an enjoyable read.

*I dedicate this thesis to my best friend and my biggest supporter, my late granddad,  
George Bennett.*

# Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Health and Life Sciences Ethics Committee at the University of Northumbria in Newcastle.

**I declare that the Word Count of this Thesis is 58,854 words.**

Name: Lauren Georgia Bussey

Signature:

Date:

# Published Work

Work from this thesis has contributed to the following publications:

Sillence, E., & Bussey, L. (2017). Changing hospitals, choosing chemotherapy and deciding you've made the right choice: Understanding the role of online support groups in different health decision making activities. *Patient Education and Counseling*, 100(5), 994-999.

Bussey, L., & Sillence, E. (2017, July). (How) do People Negotiate Online Information into their Decision Making with Healthcare Professionals?. In *Proceedings of the 2017 International Conference on Digital Health* (pp. 1-5). ACM.

Publications under review:

Bussey, L., & Sillence, E. (2018). The Internet as a multifunctional resource in health decision making. *Qualitative Health Research*.

# **Chapter 1: Introduction**

## **1.1 Introduction**

The internet is a key information resource. Recent figures report that 89% of adults in the United Kingdom used the internet between January and March 2017 (Office for National Statistics, 2017). With the current governmental and professional body drive towards collaborative decision making in healthcare (Department of Health, 2012), more patients are using the internet to support their health decision making. In the UK, the number of people sourcing health information online has almost doubled since 2005, from 37% to 69% (Blank & Dutton, 2013), and those with chronic conditions are twice as likely to consult online health information (Thackeray, Crookston, & West, 2013).

The emergence of such an accessible information resource and decision support tool means that considerable literature has explored how individuals use online health information to be better informed about their condition, to find support, and to inform their use of services (Ziebland & Wyke, 2012). Much of this literature has attended to how individuals with long term or chronic health conditions use the internet as a decision support resource (Synnot et al., 2016). Such studies have typically explored how different forms of health information e.g. statistical and narrative, differentially affect treatment choices (e.g. Osaka & Nakayama, 2017). Though such findings provide useful information regarding the effects of different online information on treatment decisions, much of this previous literature is underpinned by the concept of shared decision making (Charles, Gafni, & Whelan, 1997). This model of healthcare typically reduces health decisions down to a treatment choice offered by a healthcare professional (HCP) within the confines of a medical appointment, from which a shared decision between patient and professional is made.

There has been increasing recognition that health decision making and indeed the activities that constitute decision making are more varied and complex than previously thought (Entwistle & Watt, 2006). These decisions are often multi-layered and are informed and transformed over time, through interactions with different knowledge sources, and can occur away from the healthcare appointment (Rapley, 2008). Taking this more holistic approach to on decision making, previous research does not account for how online health information informs a broader range of health decisions other than

treatment choice, nor does it account for how individuals with shorter term health complaints use it to support their health decision making.

As internet informed patients are using and integrating online health information into their decisions, research has also explored the perspectives of healthcare professionals (HCPs) regarding their patients' use of online resources. However, current studies primarily focus on GPs, and their patients' use of the internet to inform treatment decisions, and have typically reported negative views (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Grünloh, Myreteg, Cajander, & Rexhepi, 2018). Patient based studies have identified a number of barriers and facilitators to patients integrating online health information into the appointments (Silver, 2015; Tan & Goonawardene, 2017). Given that research consistently identifies good patient-professional interactions to be important to positive health outcomes and patient satisfaction (Bylund et al., 2007; Macdonald et al., 2018), taking into account multiple stakeholder perspectives is key. This approach will encourage the generation of solutions aimed at facilitating the integration of online information at appointments, and so better recognise the distributed nature of patient health decision making.

## **1.2 Research Questions**

The aim of this thesis was to

- 1) What are the ways in which internet resources support health decision making across a range of health conditions and issues?
- 2) How can the integration of online health information into interactions with HCPs be encouraged and improved?

## **1.3 Research Objectives**

The specific objectives of this thesis were to:

- Identify the role of the internet in supporting health decision making in individuals with long term health conditions (Study 1)
- Examine how individuals with short term health complaints use online health information to inform health decisions (Study 2)
- Identify health professionals' views of the internet informed patient, and the influences on the professional-patient relationship, and consultation experience (Study 3)

- Quantitatively examine how online health information is used in health decisions, exploring the role of trust and empowerment in decision satisfaction (Study 4)
- Develop an intervention that can increase patient intentions to integrate online health information with their HCP (Study 5)

#### 1.4 Thesis approach to addressing research questions and objectives:

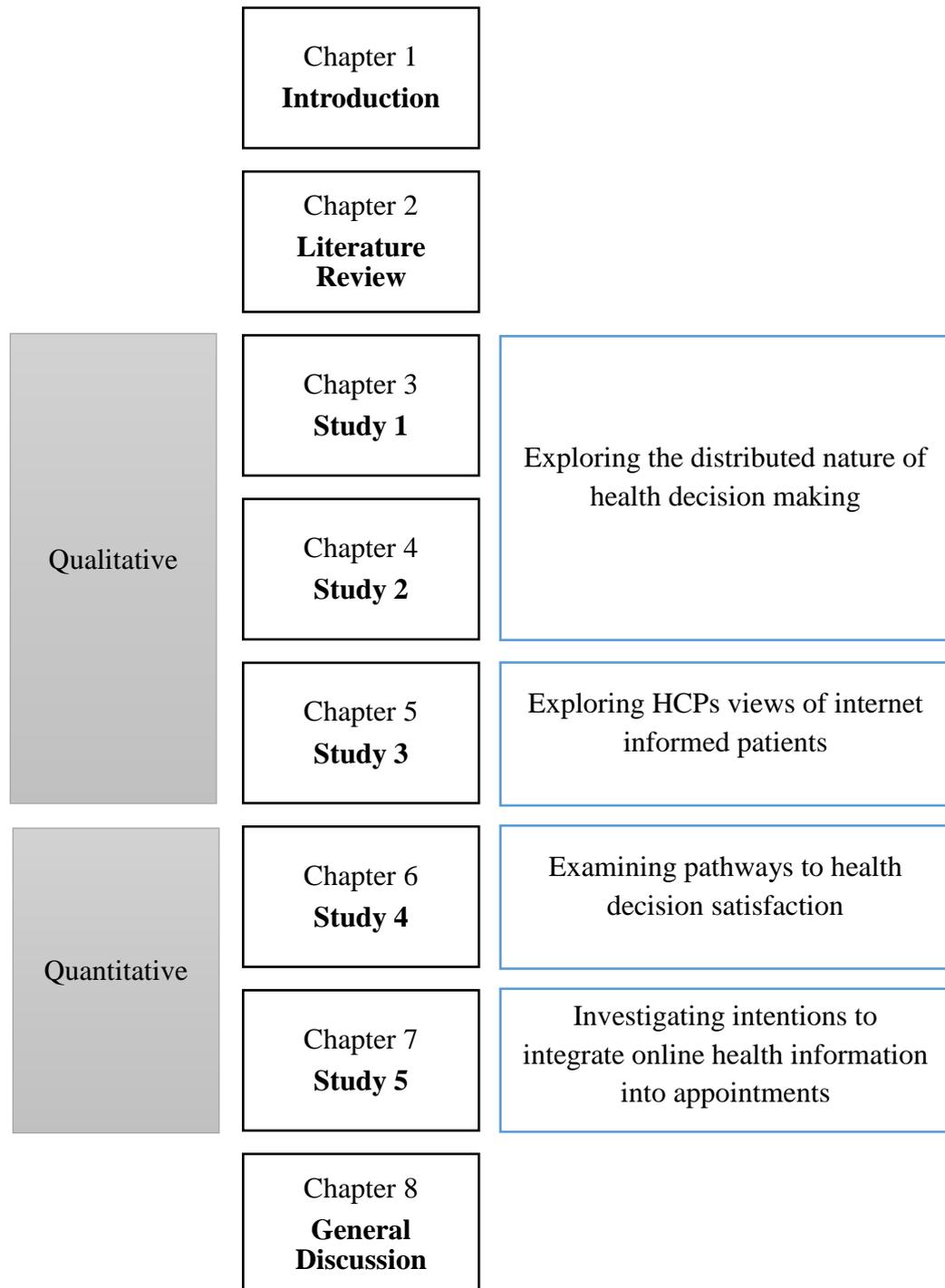


Figure 1.1. Thesis overview

The thesis aimed to examine the ways in which internet resources support health decision making across a range of health decisions and issues, and to improve patients' integration of online health information into healthcare appointments. Study 1 aimed to explore the distributed nature of health decision making in individuals with long term health conditions. Study 2 aimed to address how individuals with short term health complaints use online health information to inform health related decisions from a distributed decision making (DDM) perspective. Study 3 explored healthcare professionals view of the internet informed patient, and the impact on the patient-professional relationship and consultation. Study 4 quantitatively examined the mediating role of trust and empowerment on health decision satisfaction. Study 5 developed an intervention to increase intentions to integrate online health information into healthcare appointments.

## **1.5 Overview of Studies**

This thesis adopted a mixed methods approach. The first two studies employed qualitative methods to explore the distributed nature of health decision making in individuals with long term and short term health conditions. The third study qualitatively explored HCPs views on the internet informed patient. The fourth study took a quantitative approach to investigate mediating pathways to health decision satisfaction. Study 5 adopted a quantitative approach to investigate whether an intervention could increase intentions to discuss online health information with a HCP. The following sections provide an overview of each study and their key findings.

### **1.5.1 Study 1 (Chapter 3)**

Study 1 is a qualitative study that aimed to explore how individuals with long term health conditions use online health information to inform health decisions, from the perspective of distributed decision making. This is because previous literature has primarily considered health decision making as a singular, treatment decision, made in collaboration with a HCP within the confines of the healthcare appointment. However, literature suggests that health decision making can be distributed over time and can be transformed through interactions with people and technologies. It was important to examine individuals with long term conditions as they are encouraged to take responsibility for their healthcare, of which the internet remains a key information resource. Semi-structured interviews were thematically analysed and data presented around two themes: (1) *Empowering processes*, (2) *Integrated decision making*. The first theme describes how knowledge gained from online health information resources, and

support obtained through social media and interactions with other patients online, empowered individuals with long term health conditions to make health decisions. The second theme demonstrates individuals use the internet to inform a multitude of health related decisions, and reports on how information is integrated successfully and unsuccessfully into consultations with medical professionals, and how this affects the professional-patient relationship. These findings highlight the integrated and distributed nature of decision making, showing the involvement of multiple information knowledge sources, and the different types of decisions they can inform and transform.

### **1.5.2 Study 2 (Chapter 4)**

Study 2 is a qualitative study which explored from the perspective of DDM, how individuals with short term health complaints use online health information to inform health decisions. This was because published literature focuses on chronic health conditions and seldom considers the role of the internet as an information resource for individuals with short term health complaints. Thematic analysis of semi-structured interviews identified three themes: (1) *The internet as a triage device*, (2) *Going solo: Making the decision alone*, (3) *Information negotiation and integration*. The first theme highlighted that participants used the internet to help them decide whether or not to seek medical advice. The second theme demonstrated that online health information assisted in health decisions without needing input from a health professional. The final theme explored successful and unsuccessful integration of online health information into a healthcare appointment and the impact on the patient-professional relationship and medical consultation. The findings of this study regarding consulted sources, motivations for searching, and how information is integrated into appointments juxtapose those presented in Study 1. However, a commonality in both studies is that patients are apprehensive to discuss online health information with professionals at appointments, as they believe HCPs hold negative perceptions of internet informed patients. The findings also suggest that individuals with long term and short term health complaints differentially use online health information to support a number of different health decisions.

### **1.5.3 Study 3 (Chapter 5)**

Study 3 is a qualitative study that aimed to investigate HCPs experiences and views regarding the use of online health information in patients' health decisions. This was because participants in Study 1 and Study 2 believed HCPs held negative attitudes toward

internet informed patients, which meant that patients were apprehensive to disclose their online searching to a HCP. Excerpts from participant interviews in Study 1 and Study 2 were adapted to create five scenarios that described different ways in which participants used internet sourced health information to inform their health decisions. Health professionals commented on and discussed each scenario, whilst reflecting upon their own professional experiences. Thematic analysis highlighted two prominent themes: (1) *Being transparent and honest*, (2) *Improving integration*. The first theme describes positive perspectives held by the health professionals, who encourage patients to be honest regarding their online health searching. In the second theme, health professionals expressed concerns regarding the internet as a health information resource, but encouraged patients to integrate information into discussions with the professional, and provided recommendations how participants should integrate information. Overall, HCPs positive attitudes toward internet informed patient juxtapose participants' understandings and expectations presented in Study 1 and Study 2. This discrepancy between patients understanding of healthcare professional beliefs and their actual beliefs, regarding patient use of the internet in health decisions, suggests that patient intentions to integrate online health information into health appointments should be targeted in order to minimise this gap.

#### **1.5.4 Study 4 (Chapter 6)**

Study 4 is a quantitative study that aimed to investigate how individuals using online health information for short term and long term health complaints achieve decision satisfaction. This was because findings in Study 1 and Study 2 highlighted individuals with different condition durations have different motivations for consulting online health information, and act upon the information in different ways. A number of different pathways through which participants achieved satisfaction with their health decision making was also apparent. An online survey was administered to 196 participants to investigate the pathways through which decision satisfaction is achieved through online health information searching. When completing the survey participants were asked to think of an occasion where they had used the internet to help them with a health decision. Chi squared analyses identified significant associations between condition duration and seeing a HCP, and the types of decisions participants were making. Specifically, those completing the survey with regards to a short term health complaint were more likely to see a HCP than those with a long term health condition. In addition, individuals with a short term complaint were mostly making a treatment related decision, whereas those

with a long term complaint were mostly deciding whether to seek professional intervention. Participants who decided to see a health professional after their online searching did so to prepare for the appointment, to be able to contribute, and felt encouraged by the professional to integrate the information. Participants who did not see a health professional after their health information searching were satisfied that they could make the decision alone, wanted to avoid burdening the professional, were worried about how to integrate the information, and were concerned about the professionals reaction. Mediation analyses identified an indirect effect of trust, and patient experience information on decision satisfaction. Overall, the findings support those of earlier qualitative work (Studies 1-3); further highlighting the discordance between patient beliefs and professionals' actual beliefs about internet informed patients. Novel findings demonstrate the predictive role of affect in decision making, and provide further evidence in support for the integrated and distributed nature of health decision making.

### **1.5.5 Study 5 (Chapter 7)**

Study 1, Study 2, and Study 4 demonstrated that patients use online health information to inform health decisions, but are apprehensive to discuss online health information with HCPs as patients believe they hold negative views toward internet informed patients. However, Study 3 highlighted that health professionals held positive views toward internet informed patients and encourage the integration of this information into appointments. Therefore, Study 5 is a quantitative, experimental study that aimed to increase intentions to discuss information with a health professional. One hundred and forty women took part in a hypothetical decision making task. Participants were asked to imagine that they had been diagnosed with breast cancer and needed to make a treatment decision. Participants were randomly allocated to read one of four variations of breast cancer survivor stories on a health website. Participants read either (1) survivor story, (2) survivor story with self-reflection prompt, (3) survivor story with discussion starter prompt, (4) survivor story with both self-reflection and discussion starter prompt. Self-reflection prompts were included as previous research found that individuals reflect on message content and author characteristics when considering using it in their own health decisions. The discussion starter component was chosen as findings in Studies 1-3 highlighted participants require encouragement to discuss health information with their HCP. It was found that intentions to integrate online sourced health information with health professionals were higher when patient narratives (survivor stories) were paired with either the self-reflection component or the discussion starter component, than when

both were present. These findings suggest that intentions to discuss online health information with health professionals can be increased. However, too much information may overload patients and have deleterious effects on intentions to integrate information.

## **1.6 Original contributions of this thesis**

The original contributions of this thesis:

1. Identified the role of the internet in distributed health decision making in long term health conditions (Study 1)
2. Examined the role of the internet in distributed health decision making in short term health complaints (Study 2)
3. Identified using a novel scenario approach, discordance between patient beliefs and HCPs actual beliefs regarding internet informed patients (Study 3)
4. Demonstrated the mediating role of affective empowerment but not cognitive empowerment on health decision satisfaction (Study 4)
5. Demonstrated that patient narrative information, when paired with a self-reflection or discussion starter prompts, can increase intentions to discuss health information with HCPs (Study 5)

## **Chapter 2: Literature Review**

This chapter focuses on the existing literature pertaining to decision making and the internet as an information resource. This chapter is split into two sections to provide greater clarity around the research problem. The first section provides an overview of decision making literature, including traditional decision making theories and models and recent concepts concerning decision making in healthcare. The second section discusses the internet as a health information resource, and addresses different types of information used in health decisions and discusses key concepts such as patient empowerment and the internet informed patient.

### **2.1 Decision making**

#### **2.1.1 Cognitive decision making**

At its most basic, decision making involves selecting one option from several alternatives (Eysenck & Keane, 2013). When outcomes are uncertain, the ways in which people engage in decision making becomes of particular interest to economists, psychologists and health researchers.

Describing decision making within an economic context has typically relied upon traditional models of rational choice such as game theory, decision theory, and expected utility theory (Neumann, 1928). These models assume rationality and more recently researchers have been keen to point out that human judgement and decision making systematically deviates from standard assumptions of rationality in economics” (Pachur, Suter, & Hertwig, 2017, p.44). Moving forward, researchers have either attempted to capture these elements of human behaviour by adding in psychological constructs such as risk aversion, loss aversion and probability weighting to their models of risk preferences and choice (Tversky & Kahneman, 1992), or have taken a different approach to human decision making which draws on Tversky and Kahneman’s theoretical work on heuristics, and assumes that human judgements under uncertainty do not rely on complicated processes, but simplistic processing (Pachur et al., 2017). This second approach focusing on heuristics or ‘cognitive shortcuts’ rests upon Simon’s seminal work which describes humans as having bounded rationality and computational capacities (Simon, 1955). For decision making, this means that heuristic processing ignores the computation of probabilities, outcomes, and risk (which algebraic models describe), and focuses on the content of choice processes in terms of the cognitive operations underlying a decision e.g. search, stopping, and integration of information (Payne, Bettman, &

Johnson, 1993). Dual process models were later developed in order to account for simplistic and more complex cognitive processes employed in decision making. The heuristic-systematic model for information processing (HSM; Chaiken, 1980) and the elaboration likelihood model (ELM; Cacioppo & Petty, 1984) are dual process theories which describe human processing of persuasive information messages. The HSM proposes that information can be processed heuristically, employing a number of different judgements to judge the validity of messages, or systematically, where analytical skills judge the source reliability and message content, contributing to the overall validity judgment initiated in heuristic processing (Chaiken, 1980). Following this dual framework structure, the ELM similarly proposed that information may be processed centrally, requiring elaborations of the message dictated by the individual's motivation to consider the message, whilst peripheral processing relies on heuristic information such as the attractiveness of the information source and production of the message quality (Petty & Cacioppo, 1986).

Kahneman (2003) went on to differentiate the two processing routes described by the HSM and ELM (heuristic processing and systematic/central processing), labelling them intuition (system 1) and reasoning (system 2). According to this model, system 1 employs heuristics to generate intuitive answers to problems, this process is fast, effortless, and automatic. Answers generated by system 1 are then monitored and corrected by the system 2, which is characterised by slower, controlled, and more effortful processing.

In an attempt to address the complexities involved in real world decision making, Wright's (1984) multi-attribute theory (as described by Eysenck & Keane, 2013), describes a five-stage strategy which outlines the ideal stages of decision making. However, in accordance with Simon's (1955) argument that human processing is bound by attention and short term memory constraints, such complex strategies are rarely employed in real life decision making.

Dual process theories thus account for both systematic and heuristic message processing, however humans seem to prefer to minimise cognitive demands by utilising heuristics (Fiedler & von Sydow, 2015; Kool, McGuire, Rosen, & Botvinick, 2010). This is also sometimes the case for decisions regarding health information.

### **2.1.2 Cognitive underpinnings of health decision making**

Cumulative prospect theory (Tversky & Kahneman, 1992) can be adapted to understand decision making in health. The theoretical underpinning of Tversky and Kahneman's

cumulative prospect theory (losses and gains) states that when information presented as a ‘loss’ or in a negative light, individuals are more inclined to take risks, but less likely to take risks when the information is presented in a positive light, or as a ‘gain’ (Kahneman, 1979). These findings are also evident within health information provision and health decisions (Borah & Xiao, 2018), for example, in an analysis of messages posted on a prostate cancer message forum, Sillence and Mo (2014) found that both systematic and non-systematic information processing was present in accounts of treatment decision making. Communication researchers also identify the impact of message framing on health related behaviours (Latimer, Salovey, & Rothman, 2007). For example, loss framed messages have encouraged illness detection behaviours such as mammography screening (Schneider et al., 2001), whilst gain focussed messages promote smoking cessation (Steward, Schneider, Pizarro, & Salovey, 2003), and alcohol consumption (Bernstein, Wood, & Erickson, 2015).

Where important health decisions are at stake, it would be reasonable to expect that consumers of online health information would take the time and effort to evaluate and consider information before using it to inform a decision. However, research shows this is rarely the case, as consumers move from site to site they are likely to employ quick strategies (heuristics) to evaluate health information, often forming judgements of information credibility on website design factors such as navigability and functionality (Fogg et al., 2003). A corollary of such behaviour is the potential for consumers to make health decisions based on information that may not be applicable, reliable or credible.

Simons’ concept of bounded rationality (Simon, 1955) stipulates that limited cognitive resources often prevent rational, careful information processing. Similarly, The Limited Capacity Model (Lang, 2000) and the Prominence-Interpretation Theory of web credibility (Fogg, 2003), suggest that due to humans’ limited resource capacity, not all elements of a website will enter credibility evaluations. In terms of health information searching, consumers may employ satisficing (a form of bounded rationality), meaning that their searching stops when their needs have been met (Metzger & Flanagin, 2013). With regards to health information processing, Sillence and Mo (2014) identified that members of a prostate cancer support group reported using mostly non-systematic decision making in their online messages. Some messages, for example, demonstrated the use of the expert opinions heuristic, i.e. deferring the decision making responsibility to a healthcare professional. The availability heuristic was also apparent, as some men described making decisions that were formed on the basis of previous experience.

The information-processing models and empirical research described above, are in agreement that not all cognitive resources are employed to obtain optimal outcomes, even in situations concerning health decisions. Seemingly, in order to conserve time and effort, consumers often employ cognitive heuristics in order to deal with vast quantities of information and minimise cognitive load (Gigerenzer & Todd, 1999).

The implications of using cognitive heuristics has been debated. While some suggest they lead to accurate decisions (Gigerenzer & Todd, 1999), others argue they encourage biased or faulty information processing (Tversky & Kahneman, 1974). The role of human emotion in information processing may be relevant to this argument. A limitation pertaining to the use of cognitive heuristics in decision making, is the lack of consideration of the influential role of emotion on the decision making process. Findings suggest that loss framed messages can trigger negative emotional responses, which can affect judgements of message credibility and persuasiveness (Skalski, Tamborini, Glazer, & Smith, 2009). As such research suggests that an individual's emotional response to a message can play an important role in the message processing and subsequently impact decision making, then perhaps the role of emotion should be considered more carefully in decision making models and theories.

In summary, traditional models and theories of cognitive decision making processes agree that consumers appear to have a preference for heuristic based processing. This is also evident in the evaluation of health information to inform health decisions, as consumers who are overwhelmed by the vast amount of health information are likely to employ heuristic processing in order to minimise cognitive load.

### **2.1.3 Health decision making models and frameworks**

Researchers examining health decision making have identified a number of health decision making activities, stages, and the presence of different decisions associated with different information formats.

Entwistle and Watt (2006) proposed a conceptual framework which reflects the complexity of involvement in health decisions. The authors suggest that patient involvement in decision making extends beyond that of the patient-clinician communication, and the selection of one treatment option from many others. This framework encourages a holistic approach to viewing healthcare decisions by emphasising the presence and importance of multiple decision making stages. In this way, the framework highlights areas where health professionals can facilitate patient

involvement in decisions directly through discussions with the patient, but also draws attention to decision activities that occur outside of consultations, that are also open to patient involvement

In taking a broader perspective on decision making tasks, Entwistle and Watt (2006) identify six key decision making activities;

1. Recognition and clarification of a problem
2. Identification of potential solutions
3. Appraisal of potential solutions
4. Selection of a course of action
5. Implementation of the chosen course of action
6. Evaluation of the solution adopted

These activities extend the traditional timeline associated with decision making. They cover the period of time from before a decision was recognised as being needed to reflection on the decision itself – sometimes referred to as decision satisfaction. By drawing attention to multiple decision making activities, research can examine patient involvement in decision making from a more comprehensive perspective. In doing so, it is possible to see the integrated nature of health decisions and how the interplay between these activities can affect health outcomes (Entwistle & Watt, 2006).

The identification of multiple activities and stages involved in health decision making reflect the integrated and complicated nature of health decision making. Prior to these findings, research around health decision making largely focused on single treatment decisions that occurred after a dyadic encounter between patient and professional, within the confines of a consultation room. This concept is explored in more detail later in this chapter.

Like cognitive frameworks and theoretical models describing the processes of decision making, there are a number of theoretical models that describe decision making in healthcare. An early, prominent model of decision making within healthcare was that of the *paternalistic model*. Parsons conceptualised this as the patient assuming the “sick role” and complying with the medical regime set by the medical professional in order to get well (Parsons, 1951). The paternalistic model is thus epitomised by the passive patient role and the dominant role of the physician. According to this model, the physician is a gatekeeper of knowledge, and uses skills to diagnose and recommend tests and treatment for the patient and is seen to be a guardian of the patients best interests, and act

accordingly without eliciting the patient's preferences (Charles et al., 1997). Within this model of healthcare, the patient's role is restricted to that of being compliant with the information and interventions set by the physician, with the patient's only input being to provide consent to the treatment (Emanuel & Emanuel, 1992).

The *informed model* acknowledged the informational asymmetry between the patient and physician evident in the paternalistic model (Levine, Gafni, Markham, & MacFarlane, 1992). The informed model established that the technical knowledge that resides within the physician, and the patient's preferences and understanding of how the treatments will affect them, should be combined in order to bring about effective care and health improvements (Hurley, Birch, & Eyles, 1992; Levine et al., 1992). Although this attempts to rectify the information imbalance between professional and patient by increasing patients' knowledge of the treatment options and their effectiveness, information sharing does not always amount to a shared treatment decision (Charles et al., 1997). For example, although patients may want to be more informed of their medical situation and potential treatment options, they do not always wish to be responsible for making the decision (Beisecker & Beisecker, 1990; Ryan, 1992). This is particularly true for individuals with serious health issues, who may find difficulty in participating in the decision making no matter how informed they feel (Gray, Doan, & Church, 1990). Interventions which aim to promote shared decision making include treatment decision aids, which provide patients with relevant information pertaining to the available options and the associated outcome probabilities, and the quality of life associated with each outcome (Durand et al., 2014). Decision aids thus require more systematic processing regarding the weighing up of risk, and their effectiveness within healthcare decision making is debated in further detail later on in this chapter.

The *shared decision making model* (SDM; Charles et al., 1997) is the most accepted model of healthcare provision in contemporary healthcare, as it encourages collaboration between the patient and professional. Charles, Gafni, and Whelan (1999) describe the SDM model to differ from the paternalistic model and the informed model in three main activities; information exchange, deliberation, and decision about implementing a treatment.

With respect to information exchange, the SDM encourages two way information exchange between the patient and professional, whereas in the paternalism model and informed models, communication was one way in direction from physician to patient. In both of these earlier models, the patient was perceived as passive whereas the professional

was seen to be the main information resource and knowledge gatekeeper. However, the SDM also differs in the amount of information that is exchanged. In paternalism and informed models the professional dictated the course of action to the patient and provided minimal information. Patient involvement consisted of providing consent to the course of action. In the SDM model, the professional must provide all information that is relevant to making the decision, such as the benefits and risks associated with each treatment options, and the effects on psychological and social well-being.

The SDM approach to the deliberation process also differs considerably to the earlier approaches. The process of deliberation requires the expression and discussion of treatment preferences, particularly by the patient. Physicians who wish to adopt a SDM approach are thus recommended to create a safe environment for the patient to explore and express the available options (Guadagnoli & Ward, 1998). It is at this stage that professional and patient conflict might occur if patients have already made up their mind before the consultation.

The final way in which the SDM model differs from the paternalistic and informed models of decision making is in terms of deciding on the treatment to implement. In the paternalistic model, the physician decided upon the best treatment option for the patient, and in the informed model, the patient made the decision. In the SDM model, both parties collaborate in order to reach a mutually agreed decision, in which they are both interested and invested.

In summary, the SDM model is epitomised by the collaboration of both the patient and professional in the information sharing, information deliberation, and decision making activities. However, Charles et al. (1999) acknowledge that the model assumes involvement of only two parties within the decision making process (the patient and professional), but consider that patients may confide, consult, and share information with other parties, such as family and friends. The introduction of other influences in the decision making process adds another layer of complexity, as the patient-physician interaction represents a small aspect of a much larger, integrated decision making process that involves others external to the medical dyadic encounter. This limitation is echoed by Entwistle and Watt (2006), who explain that involvement can take many forms:

*“In everyday English, people can be said to be involved in activities and/or with other people. They are deemed to be involved not just by virtue of their visible efforts in relation to those activities or their manifest dealings with those other*

*people, but also by virtue of their thoughts and feelings about those activities and people, including the personal significance they attach to them and their sense of self-identity in relation to them” (Entwistle & Watt, 2006, p.271).*

To conclude, although the SDM model is applauded for the encouragement of patient and professional collaboration, the model does not account for the involvement of other sources of knowledge, external to patient-professional dyad within the confines of the medical consultation. Charles et al. (1999) acknowledge that between the three key models of DM (paternalistic, informed, and shared) a number of other iterations exist. However, a later theory analysis of fifteen SDM models conducted by Stacey, Légaré, Pouliot, Kryworuchko, and Dunn (2010) concluded that most still only addressed the patient-professional dyadic encounter, and failed to incorporate others such as family, friends and other health professionals who may be involved in the patient’s decision making.

Drawing on a number of empirical studies, Rapley (2008) provides evidence in support the notion of *distributed decision making* (DDM). DDM encompasses the understanding that decision making is an ongoing event that evolves over multiple encounters, is not a single solo activity but is distributed over a range of people and is transformed over a range of encounters with both people and technologies. The DDM thus aims to address the aforementioned limitations ascribed to the SDM model.

Referring to a participant’s illness narrative as a point of reference, Rapley (2008) identifies the multiple encounters involved in healthcare. For example, one participant described how attending an optician appointment led to a referral to the casualty department and then to a specialised clinic, he was then referred to a stroke consultant, vascular surgeon, GP, and finally attended a second meeting with the stroke consult to agree on a drug therapy treatment. As described previously, the SDM model represents the sharing of decisions in a one off dyadic encounter within the confines of a consultation room. This example shows how the patient learns new information about his situation and learns about possible treatment options to explore. His final decision was thus the product of a decision which was developed, shaped, and revisited in a chain of medical encounters with different professionals.

Evidence that decision making is shaped by interactions with other people is not a novel concept, as discussed previously, authors are in general agreement that the involvement of significant others in medical decisions warrants representation in decision models in

order to gather a holistic understanding of the involvement of significant others in health decision making (Öhlén, Balneaves, Bottorff, & Brazier, 2006). Rapley (2008) draws on discussions with a patient who demonstrates learning of new possible healthcare options through discussions with a friend amongst other examples. He explains that interactions with others can transform decisions, for example talking to another patient in a waiting room may present new knowledge, which is then discussed with family members at home, and the outcome of this discussion may be integrated into the next medical consultation. This highlights how decisions are transformed over time with multiple interactions with people, the temporal restrictions of the SDM model prevent such interactions from being represented within the model. It is also possible to see how different decision making activities, for example, those described by Entwistle and Watt (2006) fit well within the notion of DDM.

Finally, Rapley (2008) presents data from interactions with health practitioners, who describe their knowledge about patients to be informed by interactions with the patients themselves and interactions with the patient's family. Furthermore, consultation practises were seen to be informed by discussions with colleagues, educators, and consultations with other patients. The influence of technologies was also described, as one practitioner recalled an appointment where the patient had already researched treatment options and subsequently brought in the print outs from the internet. In this case, the patient's knowledge was used to mark agreement with the practitioner's advice and demonstrates how knowledge learned from different sources and technologies can be incorporated into medical decisions.

When considering how the landscape of patient involvement in medical decision making has progressed from the 1950's to the present day, it is pertinent to consider how changes in healthcare policy and clinical guidelines have contributed to the progression through decision models outlined within this section (2.1.3). The shift from a paternalistic method of care delivery (in the 1950's), toward the preference for patient involvement is reflected throughout healthcare policy statements of the late 1990s, which often utilise terminology such as 'collaboration' and 'partnership' (Elwyn, Edwards, & Kinnersley, 1999). Thus, the emergence of updated political and clinical healthcare guidelines are likely to have underpinned this progression from the informed healthcare model to that of shared decision making. For example, in 1991 The Patients Charter 1 stated "you (the patient) have a right to have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it"

(The Department of Health, 1991). More recent examples of health policy guidance include the collection of publications known as The White Papers, produced by the government which set out proposals for future legislature. The White Paper (2010) outlined the coalition government plans for reforming the NHS for England, including emphasis on shared decision making, for example “individuals should feel that they are in the driving seat for all aspects of their and their family’s health, wellbeing and care” (The Department of Health and Social Care, 2010, p.24). Similarly in 2012 publication of a policy paper entitled ‘Caring for Our Future: Reforming Care and Support’ (The Department of Health and Social Care, 2012), and government response to the consultation on “Liberating the NHS: No Decision About Me, Without Me” (The Department of Health, 2012), both were underlined by the recommendations to a more patient led NHS through the implementation of shared decision making within healthcare.

In the present day, discussions around NHS guidance focus on the recently published NHS Long Term Plan (2019) which describes changes to commissioning in order to tackle issues such as prevention and service improvement. Particularly pertinent to this thesis, Chapter 1 of the long term plan states five major, practical, changes to the NHS service model, including “People will get more control over their own health, and more personalised care when they need it”. It is thus plain to see how the development and publication of health policy and guidance have transformed to encourage patient involvement in healthcare, as described by the SDM.

In summary, traditional models of health decision making portray the patient as passive and accepting of information provided by the health professional. Later versions of the model were developed to incorporate a more collaborative communication between the physician and patient in order for shared DM to take place, in line with evolving healthcare policy guidelines. Although SDM is fundamental to safe and effective healthcare today (Joseph-Williams, Elwyn, & Edwards, 2014), the SDM model lacks representation of significant others involved in a patient decision, such a friends, families, and other professionals. Rapley’s (2008) notion of DDM provides a different way of thinking about health decision making. It provides detailed accounts and evidence in support for the idea that health decisions can be formed and informed through interactions with a number of people and technologies over time and can occur outside of the medical consultation.

In context of the thesis research questions presented in section 1.2, the above discussion tells us that we already know multiple sources of information are integrated into health

related decision making, however, the majority of literature has explored this within the context of SDM. The temporal element of health related decision making, as highlighted and evidenced Rapley (2008), is yet to be explored. This thesis addresses this gap in knowledge, in contribution to answering the first research question.

## **2.2 The internet and health decision making**

When confronted with a health concern, people often consult a number of information sources to help inform a health related decision such as choosing a particular course of treatment. Given the contemporary emphasis for patients to actively participate in their own health decisions (Caro, Hoffmann, Gottlieb, Kesternich, & Winter, 2014), it is increasingly important to understand how people engage with online resources to support their health related decision making. Whilst Rapley (2008) acknowledged technology in his proposal for a distributed view of health decision making in 2008, the internet has developed further since, therefore consideration for the role of the internet (in its most current form) in DDM warrants further investigation.

Section 2.1.3 highlighted how technology is a key provider of health information within the concept of DDM. Owing to the technological revolution (which is described in further detail below in section 2.2.1), consumers now have the option to utilise digital media technologies to become more knowable about their health and to provide information to healthcare providers (Lupton, 2013). FitBit and Apple Watch are examples of such technologies that enable consumers to link physiological data (e.g. steps, distances, heart rate and energy expenditure) collected using a wrist watch device, to a smartphone application where data may be saved and shared with others. Many of these applications are compatible with others such as food trackers like MyFitnessPal, thus providing a holistic snapshot of ones dietary intake and physical activity. Digital media technologies are also promoted for use in patient self-care and self-monitoring (Nunes & Fitzpatrick, 2015), with many chronic illness management applications readily available for free download, and with many others in development. For example, Nunes and Fitzpatrick (2015) report on a number of case studies whereby technology successfully supported the collaboration between Parkinson's sufferers and their carers.

In recent years, the NHS has adopted the use of technologies to support healthcare. For example, since the introduction of the electronic prescription service used in 93% of England's GP practices, patient experience has improved and has saved the NHS £136 million in the three years from 2013 to 2016. Similarly, the ability for people to book

hospital appointments online via the NHS e-Referral Service, has creating expected savings for the NHS in excess of £50 million per year (Castle-Clarke, 2018). Furthermore, the recent NHS Long Term Plan (2019) also sets out plans to further fund and utilise technology in healthcare. In particular, chapter five details the plan to upgrade technology and digitally enable care across the NHS, enabling widespread access to services, such as digital GP consultations, clinicians to access and interact with patient records and care plans remotely, and access to decision support and artificial intelligence:

*“People will be empowered, and their experience of health and care will be transformed, by the ability to access, manage and contribute to digital tools, information and services. We will ensure these technologies work for everyone, from the most digitally literate to the most technology averse, and reflect the needs of people trying to stay healthy as well as those with complex conditions”*(NHS Long Term Plan, 2019, p.93)

Thus, healthcare, and the ways in which patients may be involved in their healthcare are being encouraged and transformed in line with emerging technologies.

### **2.2.1 The internet as a health information resource**

People are increasingly seeking health information and advice online. This is reflected in statistics from the Pew Research Centre that show 72% of users typically search online for illness, treatment, and medical procedure advice (Fox, 2011). In the United Kingdom, the number of people sourcing health information online has almost doubled since 2005, from 37% to 69% (Blank & Dutton, 2013) and this number continues to rise. As a key source of health information, the internet is thus hailed a catalyst for patient power (The Department of Health, 2012). The transition from web 1.0 to web 2.0 facilitated this increased demand for internet based health information. Traditional online information sources were restricted within the nature of push media or ‘web 1.0’ whereby content was presented to users who had no control or input into the messages. Websites were therefore static in nature, acting as information portals where users passively received information. The progression of the internet to ‘web 2.0’ epitomises a state of pull media. This enables interactivity between website users, and permits active participation, collaboration and information sharing across platforms, with users being able to select information they want to receive.

The interactive and collaborative structure of web 2.0 has afforded users with the opportunity to find and share experiential and anecdotal knowledge surrounding health

and wellbeing (Yan, Sun, & Tan, 2012). This subsequent collaborative knowledge building (O'Grady, Witteman, & Wathen, 2008) has transformed the ways in which people access information about a variety of health decisions (Witteman & Zikmund-Fisher, 2012) whilst reshaping the ways in which stakeholders in healthcare communicate with one another (Han & Wiley, 2013). The internet is undoubtedly a pervasive information tool, with online health information affecting patient health decision making and health maintenance (Fox & Jones, 2009).

### **2.2.2 Health information in social media**

Social media can be defined as “a group of Internet based applications that build on the ideological and technological foundations of web 2.0 and that allow the creation and exchange of user-generated content” (Kaplan & Haenlein, 2010, p.61). Facebook, Twitter, and YouTube are well known examples of social media sites (SNSs), though social media can be more broadly categorised as forums and message boards (e.g. health focused discussion groups), media sharing (e.g. YouTube), blogging (e.g. Twitter), and review/opinion sites (Sterne, 2010). Social media can be used to network with peers, seek and provide crowd-sourced information, as well as provide social support (McCracken, 2012).

Online Support Groups (OSGs) are dedicated discussion groups for members with a certain health condition or complaint. OSGs exist within SNSs such as Facebook and as dedicated health websites and are an attractive alternative to face-to-face support groups for health information. Unique characteristics such as asynchronicity, 24 hour access, the ability for individuals to participate and contribute anonymously, and the opportunity to obtain multiple viewpoints from a diverse community may underpin their rise in popularity (Buchanan & Coulson, 2007; White & Dorman, 2001). However, OSGs are not without limitations. The lack of control over the accuracy of shared information means that members may receive misinformation (Høybye, Johansen, & Tjørnhøj-Thomsen, 2005), and the lack of social cues can prompt misinterpretation of messages that may lead to member conflict and disagreements (Malik & Coulson, 2010). Disempowering effects occur through reading negative experiences and inaccurate information (Malik & Coulson, 2010), as well as the presence of complainers and members who are unwilling to consult traditional healthcare resources (Coulson & Shaw, 2013). However, it has been concluded that OSGs improve general well-being factors such as emotional quality of life (Lieberman & Goldstein, 2005), rather than clinically significant illness factors (Barak, Boniel-Nissim, & Suler, 2008; van Uden-Kraan,

Drossaert, Taal, Shaw, et al., 2008). Though outcome studies investigating OSG efficacy have been unclear, a recent study presents a randomised control trial protocol for peer-to-peer support in the self-management of depression and anxiety (Kaylor-Hughes et al., 2017). The described protocol enables the measurement of a number of primary and secondary outcome measures, such as well-being, anxiety, social support and medical outcomes.

### **2.2.3 Internet as an empowering tool**

The term empowerment has been applied to a number of contexts, and as a result the term is used interchangeably throughout literature with patient engagement, enablement and patient activation (Risling, Martinez, Young, & Thorp-Froslie, 2017). The conceptual conflation of this complex term is perpetuated and maintained by the lack of clear definition and operationalisation (Boveldt et al., 2014). Despite inconsistent definitions and measurement, empowerment is generally viewed as a multifaceted concept with manifestations at the community, group and individual level (Menon, 2002). At the individual level, empowerment is a process by which an individual feels an increase or decrease in self-esteem/ efficacy. Group empowerment pertains to the collaboration of individuals to share knowledge, whereas community empowerment describes the social or political activities the individual participates in (Roberts, 1999). Thus, empowerment can be considered as both a process (e.g. feelings of empowerment are constructed over time) or an outcome (feeling psychologically enabled; Feste & Anderson, 1995). On this basis, and for the purpose of this thesis, empowerment is conceptualised as *“an enabling process or outcome arising from the use of online health information relating to health complaint(s), which enhances the individuals feelings and ability to inform health related decision making”*. It is important to recognise that this study also acknowledges that individuals’ perceptions of empowerment vary depending on the persons illness severity and prognosis (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008), and may fluctuate over time depending on the context (Menon, 2002; Rappaport, 1987).

The internet has been identified as a potential facilitator of patient engagement and empowerment, through providing emotional and informational support (Buchanan & Coulson, 2007; Coulson, 2005), as well as playing a vital mediating role between HCPs and patients during consultations (Kivits, 2006; Wald, Dube, & Anthony, 2007). Empowerment literature suggests the coexistence of at least three different perspectives of personal empowerment with respect to health; a propensity to comply with professional advice (the professional perspective), self-reliance through personal choice (the consumer

perspective), and the tendency to agree with collaborative knowledge learned from social exchanges (the community perspective; Lemire, Sicotte, & Paré, 2008). Traditionally, health advice was sought from a HCP, ascribing to the prescriptive version of the biomedical model (Wilson, 2001). However, in response to the growing number of online health information sources it is likely that the public's use of the internet might engage in these opportunities for personal empowerment (Lemire et al., 2008).

Numerous studies have explored the potential empowering effects obtained from participating in OSG's or networks. Initial qualitative explorations by van Uden-Kraan and colleagues (van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008), identified that exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement were all empowering processes that occurred in breast cancer, arthritis, and fibromyalgia based OSGs. Participants also described being better informed, feeling confident with their physician, treatment, and social environment, improved acceptance of the illness, increased optimism and control, enhanced self-esteem and social well-being and collective action. These empowering effects persisted in a subsequent larger scale quantitative study (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009), with 'being better informed' and 'exchanging information' identified as the empowering outcome and process that occurred to the strongest degree/most frequently. The empowerment outcome 'being better informed' is likely to have occurred through participants improved knowledge about their illness modality through peer support, as previous research indicates (Buchanan & Coulson, 2007; Campbell, Phaneuf, & Deane, 2004). The process of 'exchanging information' is likely to foster empowerment as medical professionals largely offer factual information, whereas peers offer valuable lived experiential advice. These two types of information can be used in tandem to inform health decisions.

OSGs appear to instill patients with feelings of empowerment, this finding is consistent with the benefits of OSGs identified in more recent reviews (Hess, Weinland, & Beebe, 2010; Mo & Coulson, 2014; Ziebland & Wyke, 2012). The empowerment processes and outcomes established by van Uden-Kraan et al. (2009) continue to form the basis of empowerment studies. Mo and Coulson (2014) refer to several of the empowerment effects on which they base their hypothesized model for HIV/AIDS OSG participation, empowering processes, and psychosocial outcomes. Furthermore, studies of OSG moderators indicated that their motivations and goals for the group such as 'providing more information and improving social well-being of others' (van Uden-Kraan,

Drossaert, Taal, Seydel, & van de Laar, 2010) and enabling users to proactively manage their condition (Coulson & Shaw, 2013), are in line with the empowering outcomes of OSG participation as described by participants in (van Uden-Kraan et al., 2009).

Empowering effects have also been identified within more specific aspects of healthcare, including the doctor patient relationship (Bartlett & Coulson, 2011) and treatment decisions (van Berkel, Lambooi, & Hegger, 2015). Bartlett and Coulson's (2011) findings also emphasise the influential role of OSGs on the doctor-patient relationship, as empowering processes explained 30.5% of the variance in participants' "increased confidence in the relationship with their physician", with the majority of these participants reporting satisfaction with their healthcare HCPs. However, as membership length and exchange of social support increased, participants were less likely to discuss information with their healthcare professional. Though empowerment benefitted the doctor-patient relationship, this particular finding suggests OSGs are a place of social support rather than decision making.

van Berkel et al. (2015) studied a number of OSGs (Attention Deficit Hyperactivity Disorder (ADHD), ALS and Type 1 and 2 Diabetes) and identified three main empowering processes: information exchange, sharing personal experiences, and providing empathy and support although this final category was far less prominent than it has been in previous research. van Berkel et al. (2015) found that participants are often encouraged to make decisions through consulting and collaborating with their HCP, this further supports the conclusions drawn by Bartlett and Coulson (2011) that OSGs seem to serve primarily as an information source, rather than an arena for decision making to occur.

To conclude, the growing body of literature corroborates the empowering processes and outcomes initially established by van Uden-Kraan, Drossaert, Taal, Seydel, et al. (2008). Overall, these findings show that online health information can empower both knowledge (e.g. information exchange and being better informed) and emotion (e.g. emotional support, feeling confident with their physician).

#### **2.2.4 Experiential and statistical health information and decision making**

The previous section emphasises the empowering processes and outcomes of OSGs as health information sources. Information on these sites is typically of an experiential and anecdotal nature, referred to throughout the literature as; patient narratives, patient stories, or patient experiences (PEX). However, when consulting online health information to help

with a decision people often seek traditional factual or statistical information sources, as well as others' lived experiences (France, Wyke, Ziebland, Entwistle, & Hunt, 2011; Sillence, Briggs, Harris, & Fishwick, 2007; Ziebland & Herxheimer, 2008). While statistical evidence comprises a summary of quantitative data to facilitate the understanding of important health information such as risk (Allen & Preiss, 1997), narrative information presents a cohesive story often containing information about outcomes and processes, from the author's perspective (Kopfman, Smith, Ah Yun, & Hodges, 1998). The consumption and authorship of PEx are beneficial to the health of the contributor (person supplying the information) and the consumer (the audience). For the contributor, the therapeutic experience of self-expressive writing is described as having a profound effect on the individual's emotional and physical health and well-being (Pennebaker, 1997). Meanwhile, the consumer is able to learn about the decisions involved, develop a more sophisticated vocabulary, thus improving the articulation of their health "story" (Entwistle et al., 2011; Ziebland & Wyke, 2012).

Research has also identified the importance patients place on PEx to inform specific health decisions such as diagnostic testing for foetal abnormality (France et al., 2011), considering dementia care, pregnancy termination (Entwistle et al., 2011), childhood immunization, and treatment decisions (Caro et al., 2014; Katz et al., 2011; Ziebland & Herxheimer, 2008). However, some recommend that factual information should underpin healthcare choices whilst PEx are included to provide context and add salience to factual medical information (Wyke et al., 2011; Ziebland & Herxheimer, 2008).

Hypothetical treatment decision making tasks have highlighted how influential PEx is in relation to health decisions. De Wit, Das, and Vet (2008) found that narrative information provided by a member of the participants peer group was more effective than statistical evidence (objective facts) in persuading the participant of their risk in relation to Hepatitis B and increasing their intentions to vaccinate for prevention. Similarly, when investigating the impact of varying narrative evidence (number of patient testimonials benefitting and not benefitting from a certain treatment for angina) against consistent statistical information, the inclusion of patient testimonials significantly influenced the hypothetical treatment decisions of participants (Ubel, Jepson, & Baron, 2001). However, a systematic review highlighted PEx information influenced health decision making more than the provision of statistical information in only 5 out of 17 studies (Winterbottom, Bekker, Conner, & Mooney, 2008), suggesting that PEx does not always override statistical information. However the authors identified that studies that employed first

person narratives (e.g. “I was diagnosed 3 years ago”) were twice as likely to find an effect on decision making compared with studies that employed 3<sup>rd</sup> person narratives (e.g. Sarah was diagnosed 3 years ago”), therefore inconsistent findings may be attributable to the narrative type employed in each study (1<sup>st</sup> person or 3<sup>rd</sup> person narrative).

#### **2.2.4.1 Theoretical underpinnings information bias**

The seemingly persuasive influence of PEx information upon decision making may be explained by the availability heuristic (Tversky & Kahneman, 1973), as narratives comprise vivid accounts that are quickly and effortlessly retrieved when making decisions. This is because narratives are able to convey contextual social and emotional information absent from traditional health information resources such as patient decision aids (Lowe et al., 2009), and it is these aspects that have the potential to immerse the audience in the story and ensure effective information transfer (De Wit et al., 2008). This supports the idea that human brains process stories differently than other input forms (Newman, 2004).

Theories of persuasive communication highlight how audiences process narrative information and the resultant changes in behaviour. According to the Elaboration Likelihood Model (Cacioppo & Petty, 1984), personal relevance of the story dictates the information processing route. Central processing occurs when audiences evaluate and determine message to be valid, and change their attitudes in congruence with the portrayed message. Peripheral processing is engaged when the reader assessed message credibility and source attractiveness (Perrier & Martin Ginis, 2017). The Transportation Imagery Model (Green & Brock, 2002) also suggests that audiences’ immersion in a story is dependent on their engagement with the message, narrative quality and identification with the characters.

Together, dual process models, and the availability and affect heuristics propose that narratives influence healthcare decisions by operating along different information processing routes than other message formats (Shaffer, Hulsey, & Zikmund-Fisher, 2013), and encourage the use of simple heuristics as opposed to more conscious, systematic cognitive processes (Winterbottom et al., 2008). Resultantly, more weight might be applied to narrative information in decision making (Shaffer, Hulsey, et al., 2013).

#### **2.2.4.2 Reconsidering how PEx is examined**

The majority of previous research attempts to understand whether PEx or statistical information has the most impact on health decisions. However, recent investigations suggest that these two information types should not be presented as opponents and that rather than one type having the most persuasive influence on decision making, it is more likely that different types of information will have the strongest effect on different outcomes. Zebregs, van den Putte, Neijens, and de Graaf (2015) found statistical information to have a stronger influence than narrative information on beliefs and attitude, and narrative information had a stronger influence on intention. These findings are in line with prior research that has also identified statistical and narrative information to each benefit a different outcome variable (De Wit et al., 2008; Greene & Brinn, 2003). This is an important finding given that behavioural intentions are perceived as the immediate determinant of behaviour (Ajzen & Fishbein, 1980), suggesting that narrative information is most likely to affect behaviour. Meta-analyses have identified affective responses to strongly impact intentions (Sandberg & Conner, 2008; Winterbottom et al., 2008), and narrative information has shown to trigger more affective responses than statistical information (Kopfman et al., 1998; Mazzocco, Green, Sasota, & Jones, 2010). Therefore, it could be suggested that narratives impact behavioural intentions as the type of information they contain differs to that of statistical information formats, suggesting affect to be an active ingredient of narratives.

These findings are interesting, given that both statistical and PEx information are utilised within Patient Decision Aids (PDAs). PDAs increase patient knowledge and more accurate expectations regarding benefits and harms (Stacey et al., 2017), and are successful in promoting conversation and shared decision making (Coylewright et al., 2014). The inclusion of PEx information within PDAs has generated much discussion (Elwyn et al., 2006) owing to their reputation to bias patient decisions, as previously discussed. However a critical review by (Bekker et al., 2013) concluded there was insufficient evidence to suggest that addition of PEx in decision aids increased effectiveness to inform decision making. Although, PDAs that comprised PEx produced greater recall of facts, and increased interest in screening behaviours. On the whole, findings therefore point to the conclusion that success of statistical or narrative information is dependent upon the outcome variables of interest; i.e. beliefs, attitudes of behavioural intentions (Zebregs et al., 2015). Ultimately, both forms of information are useful to health decision making and should be used in tandem to support decisions.

Shaffer and Zikmund-Fisher (2012) suggest that the purpose of narratives can be used to inform, engage, model behaviour, persuade, and comfort, with different outcomes associated with each of these variations. For example, increased participation in health decision making is reported when the purpose of the narrative was to model a targeted behaviour (Wise, Han, Shaw, McTavish, & Gustafson, 2008). However, greater message engagement occurs when the purpose of the message was to engage the audience in the narrative.

Recent research findings highlight the complexity of PEx information as a decision aid. Shaffer and Zikmund-Fisher (2012) present a taxonomy that shows how PEx in decision aids differ in their purpose, content, and evaluative valence. The authors therefore conclude that narratives should be reconsidered as multidimensional, given that certain aspects can differentially affect decision making. Narrative content refers to characteristics of the message such as outcomes (e.g. description of psychological and/or physical health outcomes), patient experiences (e.g. feelings and experiences regarding treatment), and process narratives (cognitive account of how the patient made a particular health decisions). In this case, the authors suggest that “each of the three narrative content categories will be processed differently, leading to unique effects on decision making” (Shaffer & Zikmund-Fisher, 2012, p.8). For example, it is postulated that outcome narratives influence the availability of the outcome described in the narratives, thus affect risk perception (Betsch, Ulshöfer, Renkewitz, & Betsch, 2011; De Wit et al., 2008), and process narratives draw attention to new knowledge which may influence evaluations of the decision process (e.g. feel more confident and prepared to make a decision). In a later study Shaffer, Hulsey, et al. (2013) further investigated the effects of process-focussed and experienced-focussed narratives on decision making, and found process narratives increased information search behaviours, whilst experience narratives improved evaluations of the decision process.

Lastly, evaluative valence describes the tone of the narrative to range from extremely positive to extremely negative. The polar opposites may affect decisions as they induce different processing models. Like Skalski et al. (2009), Shaffer and Zikmund-Fisher (2012) propose negative valence to promote negative mood, and there is a body of research to suggest that mood or affect can trigger different information processing route than positive mood (analytical reasoning is triggered rather than default processing; (Isen & Means, 1983).

Overall, these findings suggest that narratives should therefore be viewed as multidimensional rather than homogenous as typically portrayed in the research literature, and that this perhaps explain the differential effects of narrative PEx on decision making throughout the literature.

### **2.2.5 Consumer evaluations of online health information**

The volume of health information on the internet presents consumers with a challenge in terms of searching, selecting and evaluating information. Consumers make judgements on information by assessing its credibility and trustworthiness.

Throughout psychological literature, the terms ‘trust’ and ‘credibility’ are used interchangeably, due to the lack of consistency in defining these terms (Sbaffi & Rowley, 2017). For the purpose of this thesis, credibility is considered an antecedent of trust as in previous literature (Rowley, Johnson, & Sbaffi, 2015).

Research regarding consumers’ evaluations of information focus on three key dimensions; source credibility, message credibility, and media credibility (Metzger, Flanagin, Eyal, Lemus, & McCann, 2003). Source credibility describes the expertise and trustworthiness of the message sender (Hovland & Weiss, 1951), and message credibility regards characteristics of message which make it more or less believable (Fogg et al., 2001). Media credibility refers to the medium through which the message is sent or presented (Hu & Sundar, 2010).

In the age of collaborative knowledge sharing online, authorship indicators seldom accompany curated online information. Such markers are considered crucial for information credibility assessments. For example, research findings indicate that when authorship indicators are apparent, information provided by expert authors were rated significantly more credible than messages with non-expert cues (Dong, 2015; Major & Coleman, 2012; Thon & Jucks, 2017).

With respect to message content, the lack of quality standards means that shared knowledge online is not subject to scrutiny and does not require vetting by knowledge gatekeepers. This means that information is often incomplete, inaccurate, and subject to misinterpretation (Metzger et al., 2003), which can have deleterious implications within the context of public health (Borah & Xiao, 2018; Ho, McGrath, & Mattheos, 2017; Jin et al., 2014) as consumers may act on poor information. On the other hand, credible messages boast the ability to improve the effectiveness of health promotion campaigns (Mutti-Packer et al., 2017). Though often considered discretely, source and message

credibility sometimes come hand in hand. For example, the hyperlinked structure of the internet means that as consumers follow links to more information, source and message information become easily confused and disassociated (Eysenbach & Köhler, 2002), making credibility evaluations difficult to perform.

Channels of health information provision overlap, as health information is presented across official news websites and social media (Walther, Wang, & Loh, 2004). This conflation of health information delivery mediums means that some consumers do not distinguish between the source and medium channels through which they receive health information messages (Sundar & Nass, 2001). Thus, distinguishing between mediums of information provisions is more complicated in an online context, this means that credibility assessments of source, message and medium are often not considered individually, but are amalgamated to inform an overall trust of the website and the information (Klawitter & Hargittai, 2018).

Researchers have identified a number of specific heuristics that inform website credibility judgements (Metzger & Flanagin, 2013), however the employment of cognitive shortcuts (heuristics) when determining the credibility of health information can have dangerous health consequences. In an experimental manipulation of health messages on Facebook, Borah and Xiao (2018) identified that greater social endorsement in the form of “likes” increased consumer’s credibility assessments. This ‘bandwagon’ heuristic acts on the premise that the message has been subject to collective filtering and endorsement by other users, ensuing that there a general agreement that the information is correct and credible (Sundar, 2008). If consumers employ endorsement heuristics to inform credibility assessments regarding PEx information, this, teamed with the absence of source authorship indicators, means they may make health decision on the basis of poor health information.

#### **2.2.5.1 Staged model of trust**

The literature on consumer evaluations of websites is mixed with some researchers pointing to a reliance on cues such as the design of the website (Corritore, Kracher, & Wiedenbeck, 2003) and others highlighting factors such as the accuracy and comprehensiveness of the information (Stvilia, Mon, & Yi, 2009). Staged models of trust (Briggs, Burford, De Angeli, & Lynch, 2002; Sillence, Briggs, Harris, & Fishwick, 2006a) have attempted to reconcile these findings. These models suggest that consumers first employ heuristic processing to assess the design and perceived usability features of

the site, then rely on more analytical processing to judge the information quality (Briggs et al., 2002).

In support for the initial heuristic processing stage, visual cues such as website design, graphical characteristics, and presence of advertisements are acknowledged as early identifiers for trustworthiness (Beldad, De Jong, & Steehouder, 2010; Machackova & Smahel, 2018; Sillence et al., 2006a). Superficial features like the presence of advertisements can lead to suspicion of information, negatively affecting participants' perceptions of PEx genuineness and website trustworthiness (Sillence, Hardy, & Briggs, 2013; Walther et al., 2004). These findings can be explained by the Technology Acceptance Model (TAM: Kim & Park, 2012) which describes individuals' health-related internet use to be influenced by perceptions of usefulness, ease of use and attitude toward internet use (Davis, 1989). Thus, the presence of visual cues such as advertisements are synonymous with low perceptions of trust, as they indicate vested interest in providing certain information (Rains & Karmikel, 2009; Walther et al., 2004), and may negatively implicate users' perceptions of the website purpose and usefulness. Design features such as ease of use has significantly and positively affected online trust ratings (Zahedi & Song, 2008) and indirectly affects trust via credibility assessments (Corritore et al., 2003). This initial phase corroborates earlier discussions pertaining to consumers' credibility assessments of the information source.

The second processing stage requires more effort as users engage more analytical processing strategies to scrutinise intricate details of health information to inform trust evaluations. Information quality (characterised by features including completeness, accuracy, and relevance) has shown to effectively predict trust in online sources (Harris, Sillence, & Briggs, 2011; Mun, Yoon, Davis, & Lee, 2013). For example, users who check information accuracy by corroborating findings across multiple sites are more likely to trust the site (Bernhardt & Felter, 2004) and follow the advice it offers (Harris et al., 2011). Source credibility, defined as "judgments made by a perceiver concerning the believability of the communicator" (O'Keefe, 2002, p.181) is another marker of information quality and is judged on the basis of author and platform characteristics. Participants attribute high ratings of information credibility when information presented on general internet websites was authored by experts, and only when laypersons authored information presented on blogs (Ma & Atkin, 2017). Inevitably, consumers hold different expectations of health information provision across different platforms (Lin et al., 2015), therefore it is also likely that source attributions such as perceived homophily may affect

participant perceptions of website and information trust. Homophily is the “degree of perceived similarity a receiver ascribes to a message source” (Wang, Walther, Pingree, Hawkins, 2008, p.359) and is associated with network satisfaction in online discussion groups (Wright, 2000), positive evaluations of information quality and likelihood to act on advice (Wang et al., 2008). This is also apparent across health websites, where information and author relevance can engage consumers with online information (Sillence, Hardy, Harris, & Briggs, 2014). This second phase encompasses consumer use of heuristics and more effortful evaluations of message content, in order to inform overall trust in the information.

In summary, when facing the volume of health information online, consumers appear to employ heuristic processing strategies in order to initially filter relevant information, before employing slower, systematic processing to inform trust evaluations. Individuals searching for health information present a greater motivation to engage in both heuristic and systematic processing (Ma & Atkin, 2017).

#### **2.2.5.2 Health and e-Health Literacy**

Information quality is the extent to which information is; accurate, complete, understandable, current and relevant to the individual (Ghasemaghahi & Hassanein, 2016), and is considered a foundation for good decision making (Petter, DeLone, & McLean, 2013). Significant positive relationships between information quality and online decisions and satisfaction (an affective state indicating an emotional reaction to the online experience (McKinney, Yoon, & Zahedi, 2002) are noted throughout literature (Bellman, Lohse, & Johnson, 1999; Chung & Shin, 2010; Petter et al., 2013).

e-Health literacy is reported to affect evaluations of information quality (Stvilia et al., 2009). Health literacy can be defined as the degree to which consumers have the capacity to obtain, process, and understand health information (Diviani, van den Putte, Giani, & van Weert, 2015). Thus, e-Health literacy is the ability for individuals to obtain, process, and understand online health information (Jordan, Buchbinder, & Osborne, 2010). Consumers’ ability to participate in health decision making is therefore dependent upon their level of health literacy/ e-Health literacy (Diviani et al., 2015).

A key concept within the e-Health literacy literature is that of the digital divide. An amalgamation of research findings demonstrate that those of older age, low Socioeconomic Status (SES), and education, are deprived of some health information, in spite of increased internet availability access (Bawden & Robinson, 2009).

Research has identified individuals of low SES and those who are chronically ill to have significantly lower e-Health literacy than well-educated individuals. Well educated online health information seekers have better internet access, and consult significantly more information sources, search more content, and evaluate the information more than those with lower health literacy (Neter & Brainin, 2012). However, good health literacy can have unfavourable influences on the diffusion of health information. For example, health information seekers with high levels of health literacy sometimes choose not to actively share health messages because they deem them of low personal value/use, rather than considering whether the information may be useful to others in their online social networks who may be of lower health literacy (Crook, Stephens, Pastorek, Mackert, & Donovan, 2015). Therefore, good health literacy can have potentially negative implications on health information sharing more broadly.

Like the chronically ill, older adults are also considered a vulnerable group characterised by poor health literacy (Agree, King, Castro, Wiley, & Borzekowski, 2015). Though older adults may lack basic computer skills, the age-based digital divide is closing as individuals who are more familiar with computers begin to enter old age. Computer proficiency aside, research highlights that perceptions of screen content change with age and can affect the location and understanding of online health information (Agree et al., 2015). As older adults report feeling inexperienced, confused and frustrated in internet use, findings suggest that e-Health literacy amongst older adults can significantly affect trust perceptions (Zulman, Kirch, Zheng, & An, 2011).

Poor health literacy may result in information misinterpretation (Benotsch, Kalichman, and Weinhardt (2004), and may negatively impact trust perceptions in potentially valuable health information resources (Thiede, 2005; Ye, 2010). For example, higher education level significantly predicted perceived website trust (Paige, Krieger, & Stollefson, 2017), and demonstrated positive relationships in a meta-analysis (Diviani et al., 2015). Other studies also bring to light the differences in e-Health literacy levels and information evaluations. It is reported that those with lower e-Health literacy have a distorted perception of online health information credibility, often attributing high information quality ratings to poor quality information websites (Benotsch et al., 2004). This may be attributable to the differential use of evaluation criteria, as (Mackert, Kahlor, Tyler, & Gustafson, 2009) revealed individuals with low health literacy rely upon indicators of website quality that do not fit with established evaluation criteria (Kim, Eng,

Deering, & Maxfield, 1999), such as website image quality and position in the search results (Mackert et al., 2009).

In light of this, interventions aiming to improve comprehension and understanding in individuals with low health literacy, focus on design adaptations (Sheridan et al., 2011) such as the addition of video to verbal narratives (Jay et al., 2009; Yeung et al., 2017). Studies have noted that visual presentations of information either in the form of video (Shaffer, Owens, & Zikmund-Fisher, 2013) or pictograph (Tait, Voepel-Lewis, Zikmund-Fisher, & Fagerlin, 2010) are particularly beneficial in individuals with low health literacy, as video information requires less effort than reading (Shaffer, Owens, et al., 2013).

Individuals with low health literacy make poorer health decisions and have poorer health outcomes compared to individuals with higher health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Reyna & Brainerd, 2007). High health literate consumers gain better health outcomes such as improved health management and discussions with physician, than low health literate individuals (Neter & Brainin, 2012). Low health literacy may therefore present a barrier to health information seekers (patients) discussing information with their health professional. Potentially, consumers may be worried that they have misinterpreted the information or are perhaps embarrassed to admit their internet searching was motivated by a lack of health knowledge, this is discussed in the next section.

### **2.2.6 Integration**

Involved patients report using online health information to help prepare for and to complement healthcare appointments (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010), so that they can ask more questions (Iverson, Howard, & Penney, 2008), feel better equipped to collaborate and negotiate health information with the HCP (Townsend et al., 2015), and are more empowered in managing their health and in making health decisions (Rider, Malik, & Chevassut, 2014). This level of patient involvement epitomises the shift in healthcare from the traditional paternalistic model whereby patients complied with the health professional's recommendations, to a one of mutual participation (Townsend et al., 2015) and shared decision making. This shift is reflective of the UK governments "no decision about me without me" initiative (The Department of Health, 2012).

Though 75% of patients bring online health information into the HCP appointment (Malone et al., 2004), less than half of web users reveal the information to the HCP (Bylund et al., 2007). Patients report feeling embarrassed to disclose their internet searching (Silver, 2015), believing that they do not possess the skills to appraise online health information for its credibility or validity, and do not feel skilful to articulate how the information relates to their own health (Tan & Goonawardene, 2017). Patients perceived lack of skills and confidence to discuss online health information with a health professional may be in part attributable to the individual's health literacy levels. Other patient reported barriers that prevent the integration of online health information into consultations are; fear of the HCP reaction, discouragement from the HCP, and believing that there is no need to bring it up (Joseph-Williams et al., 2014; Silver, 2015; Tan & Goonawardene, 2017).

A particularly important barrier that reflects tensions in the new healthcare model is that patients do not wish to challenge or disrupt the patient-professional relationship, and believe the ramifications of discussing online information may lead to them being perceived as troublesome or challenging (Hay, Strathmann, Lieber, Wick, & Giesser, 2008; Rider et al., 2014; Ziebland et al., 2004) and may result in poorer care quality (Fraenkel & McGraw, 2007). Many patients thus endeavour to maintain the doctor-patient relationship by being mindful of the consequences of overtly disclosing online sourced health information. As a result, patients may behave in a way that they consider to embody the "good patient" such as being passive and compliant (Joseph-Williams et al., 2014).

Early studies exploring HCPs views of internet informed patients, such as those reported by (Ahmad et al., 2006), held generally negative views toward patients introducing online health information into the appointment, claiming confused patients were a product of poor online health information quality, and contributed to distress when patients performed detrimental self-diagnoses. Longer consultations and unnecessary investigations were also described as upshots of patient internet searching (Potts & Wyatt, 2002). However, recent investigations examining the HCPs' perspective demonstrate an overall positive response to internet informed patients (Van Riel, Auwerx, Debbaut, Van Hees, & Schoenmakers, 2017; van Uden-Kraan, Drossaert, Taal, Smit, et al., 2010). HCPs in Macdonald et al. (2018) adopted a positive discourse of collaboration, engagement, and empowerment, attributing benefits of internet informed patients to the HCP-patient relationship.

Physicians in Ahmad's (2006) study thought that internet informed patients lacked trust in their health provider and felt the need to defend their diagnosis or treatment plans. Encouragingly, recent research indicates that patient trust with the health provider has not been negatively affected, rather that empowered patients are equipped to contribute to discussions and are eager to learn about their care (Li, James, & McKibben, 2016; Macdonald et al., 2018). Research also showcases the role of the HCP, highlighting that their reaction to their patients attempts to integrate the information, and their own communication styles play a role in the relationship, and can affect the overall success of the communication (Caiata-Zufferey & Schulz, 2012; Franklin et al., 2018).

The patient and professional roles within contemporary healthcare are changing. In a recent survey, GPs described patient online searching to have positive effects on the consultation, facilitating knowledge exchange and helping the patient contribute to diagnosis (Van Riel et al., 2017). Furthermore, the GPs acknowledged that the opinions of relatives had a greater impact on some health decisions, suggesting a shift in thinking as GPs become more aware of the multiple influences on the patients' health related decision making, lending support to the notion of distributed care and decision making (Rapley, 2008). Early concerns that physicians feel unprepared to deal with internet informed patients (Ahmad et al., 2006) continue to receive attention. Roper and Jorm (2017) recommend that teaching should focus on changing medical students' attitudes towards the internet informed patient, in order for them to better communicate and partner with patients as we proceed to the next stages of the digital revolution in healthcare. Patient accessible electronic health record systems, for example, pose a new challenge in healthcare, as patients gain access to another source of health information. Although the information is authored by the GP and ensures credible, trustworthy, correct information, physicians can hold negative attitudes towards the ways in which patients use the information, with one physician construing negative motivations when patients consult the electronic health record, asking "Why do they need to check me?" (Grünloh et al., 2018).

### **2.2.7 Considering previous research methodologies**

The profusion of illness related information on the internet has encouraged studies to consider how people search for and use health information in their health decision making. Many different qualitative methodologies such as focus groups, semi-structured interviews and observation studies have been employed to investigate health information seeking on the internet (Bernhardt & Felter, 2004; Lee, Hoti, Hughes, & Emmerton,

2014). However, qualitative studies often employ a specialised sample such as young women diagnosed with cancer (Balka, Krueger, Holmes, & Stephen, 2010), low literacy adults (Birru et al., 2004), and students (Hargittai & Young, 2012). Furthermore, participants are often required to complete a specific task, such as using the internet to find answers to health scenarios (Senkowski & Branscum, 2015). Organic health information searching is seldom examined, this means that real life information searching processes and strategies are rarely represented in the literature. Furthermore the reliance upon retrospective memory and social pressures attributed to the face-to-face interview and focus groups, means that often participants are not able provide detailed information due to recall difficulties or are uncomfortable speaking in a group.

Traditional qualitative methodologies are being adapted and applied to different topics of research. For example, the think aloud protocol (Ericsson & Simon, 1993) is becoming more prominent throughout literature aiming to understanding consumers' health information seeking processes. This protocol encourages participants to talk whilst searching for health related information on the internet, and is considered advantageous as the method seeks to fill the gap between what consumers say they do, and what they actually do (Macias, Lee, & Cunningham, 2017). However, studies that employ the think aloud methodology often require participants to respond to constrained scenarios that do not reflect the participant's interests (Buhi, Daley, Fuhrmann, & Smith, 2009; Senkowski & Branscum, 2015), meaning that findings do not capture the participants organic information search process. On the other hand, studies which employ the think aloud technique that do encourage participant free search of health information, yield detailed findings which capture the participant's natural searching process (Macias et al., 2017). Lee, Thompson, Whybrow, and Rapley (2016) compare three forms of interview for understanding online information seeking; interviews (recall), researcher-led observation (joining participant at the computer), and diaries. The most successful approach was the researcher-led observation 'talking while searching', as participants in these interviews offered insights into the ways in which information was (dis)regarded and the ways in which looking is performed on a website. Importantly, participants described how they distinguished between information which they had purposefully searched for, and those which they came across but were stumbled upon. In comparison, the first approach of the typical interview setting, brought with it difficulty in participant recall, and in discriminating between information sources. The scrapbook or diary approach has been conducted in earlier research (Sillence, Briggs, Harris, & Fishwick, 2006b), but yielded

little information and had low compliance, though had the propensity to inform discussions and insight into participants thoughts at that time.

Quantitative studies have been widely used in e-Health studies. For example, online questionnaires have been employed to examine empowering processes and outcomes of OSGs, as well as testing participation levels between active users and lurkers (Bartlett & Coulson, 2011; Mo & Coulson, 2014). Though questionnaire methods can achieve substantial participant sample sizes, the cross sectional nature in which they are often employed prevent causality assumptions. For example, it is considered that empowerment can change over time (Zimmerman, 1995), however the cross sectional use of questionnaires means that assumptions cannot be drawn regarding empowerment as a causal factor to OSG use, or vice versa.

Investigations that examine the influence of different health information types on health decisions (particularly treatment decisions) and behavioural intentions are typically employed using hypothetical decision making tasks (Caro et al., 2014; Shaffer, Hulse, et al., 2013). These methods are often employed to examine the influence of PEx versus traditional information resources as described earlier in this chapter. However, a noted limitation of hypothetical decision making tasks is that patients are notoriously poor at anticipating how they will feel about medical procedures, relating to a certain condition (Halpern & Arnold, 2008; Ubel, Loewenstein, Schwarz, & Smith, 2005). Thus, findings from these studies should be considered as preliminary, with the expectation that future research can investigate this further in a sample facing a health concern in order to obtain a more accurate picture of the differential effects of process and experience narratives on decision making.

Experimental studies have tested aspects contributing to health website and information, such as design features and source/ authorship cues, in order to test the impact on credibility and trust assessments (Borah & Xiao, 2018). Observation studies incorporate software tracking information in order to investigate the process of searching and using e-Health information (Hansen, Derry, Resnick, & Richardson, 2003). However a popular experimental method is the use of eye tracking technology, which has been used to examine participants processing of health messages and the effects on information recall (Bol et al., 2016), and has identified that individuals with different levels of health literacy differentially visualise health information online (Mackert, Champlin, Pasch, & Weiss, 2013). It has also been used to investigate credibility assessments, one study identified

the influences of different interfaces presentation of search engine results pages and influence on source evaluations (Kammerer & Gerjets, 2012).

Research into e-Health has typically adopted a ‘toolbox approach’ to methodology picking different methods to suit the research aims and context of study. A combination of quantitative and qualitative research methods have been used both with their advantages and disadvantages. This thesis takes a mixed methods approach to investigating the use an integration of online information in health decision making, and presents rationales for the use of qualitative interviews, online survey, and hypothetical decision making tasks throughout the appropriate chapters.

In context of the thesis research questions presented in section 1.2, and upon reflection of the above discussion of published literature (in brief), we know that the internet is an empowering information resource, particularly in individuals with chronic health conditions. What we do not yet know, is how people with short term health conditions use online health information in their health decision making within the context of a distributed decision making approach. This thesis sought to address this gap in knowledge (research question 1). Secondly, we also know that although online health information is consulted and integrated into health decision making, and that there is some apprehension in patients discussing online health information with health professionals at appointments, due to a largely negative representation of health professional’s views in the literature, with only recent studies demonstrating a shift toward a more positive perspective. What requires more careful consideration, particularly in light of the NHS Long Term Plan which emphasis the progression and integration of technology in healthcare, is whether we can increase collaborative partnerships between patient and professionals to benefit health decision making. This thesis also addresses sought to address this issue (research question 2).

### **2.3 Rationale**

This chapter has provided an overview of the literature on cognitive models and theories for decision making and health decision making and has considered the internet as a health information resource. From the literature review three key issues are apparent. First, models of health decision making have developed from models rooted in cognitive, rational thinking, and do not consider the impact of human affective responses on decisions, despite research demonstrating their influence. Secondly, models of health decision making employed within contemporary healthcare (SDM) fail to represent the

distributed nature of health decision making. Research seldom considers health decision making to involve multiple decisions, multiple knowledge and information sources (including the internet), nor does it represent the transformational nature of decisions over time. Much of the literature described in this chapter has explored the role of the internet in healthcare and health decisions with samples suffering with chronic health conditions, such as diabetes and HIV. In comparison, research has seldom considered how individual with short term health complaints use the internet to support their decision making. These three issues are addressed in this thesis.

## **Chapter 3: The use of internet sourced health information for health decision making in individuals with long term health conditions (Study 1)**

This chapter describes the findings of a qualitative study designed to understand how individuals with long term health complaints search for and use online health information to inform health related decisions. Whilst the use of the internet by people with long term health issues continues to be a topic of interest in the literature, this study focuses specifically on decision making. Taking into consideration Rapley's (2008) notion of DDM, this chapter examines how people understand the role of the internet in supporting their health decision making across time, across resources and across different stakeholders.

### **3.1 Introduction**

Long term health conditions are often described as conditions which cannot be cured in most cases, but which can have a major impact on people's everyday lives (Institute for Public Policy Research, 2014). Although most people have searched online for health related information (Blank & Dutton, 2013), those with chronic or 'long term' health conditions are reportedly twice as likely to consult online health information (Thackeray et al., 2013). One reason for this is that individuals with chronic/ long term health conditions are encouraged to become more engaged and self-sufficient in their condition management and should assume an increased role of responsibility in their health decisions and healthcare (The Department of Health, 2012).

Studies of chronic health conditions such as multiple sclerosis (MS) have highlighted the ways in which patients and their carers have used online information to manage their illnesses (Lee, Hoti, Hughes, & Emmerton, 2014a; Synnot et al., 2016). As discussed more extensively in Chapter 2 (Literature Review) the majority of studies examining decision making and the internet have focused solely on treatment decisions (see Osaka & Nakayama 2017; and Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2012, for a review). A small number of studies have also highlighted the ways in which online resources can provide support for decisions around practical issues such as applying for power of attorney (Sillence, Hardy, Briggs, & Harris, 2016) .

As discussed in Chapter 2, there are multiple types of decision making activities involved in health decision making (Entwistle & Watt, 2006; Rapley, 2008). Despite this, research continues to reduce the concept of 'health decisions' to mean 'treatment decisions'. For

example, studies investigating the competing roles of static and PEx information in decision aids examine their impact on treatment decisions, but do not consider how such information may also contribute to decisions to purchase products or services to support healthcare. Furthermore, considerable literature focuses on the role of online health information searching on the patient-professional relationship and consultation. This focus on the dyadic relationship may be ascribed to the emphasis for mutual collaboration and participation, and SDM in healthcare. However, criticisms of the SDM model highlight the involvement of significant others in health decisions (Rapley, 2008), thus, SDM models and the majority of research literature, seldom considers the influence and involvement of multiple knowledge sources in an individual's health decision making. For example, in OSGs, van Berkel et al. (2015) found that participants are often encouraged to make decisions through consulting and collaborating with their HCP, which suggests that also patients are not consciously aware of the distributed nature of health decision making.

## **Rationale**

The abundance of literature pertaining to how individuals with chronic (long term) health conditions search for, use, and integrate online health information into treatment decisions is unsurprising given the contemporary emphasis for these individuals to take a more active role in their healthcare. However, the literature focuses on how individuals with chronic health conditions use online health information in their treatment decisions, and seldom addresses the role of other information sources i.e. friends, family or health decisions more broadly. Therefore, the aim of the current study is to investigate how individuals with long term health conditions use online health information to support their health decision making. In answering this study's aim, a DDM approach guides consideration of multiple decision types, information sources and information integration.

## **3.2 Method**

### **3.2.1 Analysis approach**

To address the study aim, this study took a qualitative approach. Qualitative data obtained from semi structured interviews was thematically analysed following Braun and Clarke's (2006) proposed phases of Thematic Analysis. This method was selected owing to its theoretical flexibility and ability to provide a rich and detailed complex account of data (Braun & Clarke, 2006).

In this study, thematic analysis has been conducted within the social constructivist paradigm, this epistemological standpoint advocates human meanings to be constructed frameworks as opposed to directly reflecting the real (Raskin, 2008). According to constructivism, knowledge is constructed through interaction with the world, therefore meaning and experience are produced socially and do not reside and await discovery (Gordon, 2009).

In consideration of the aforementioned epistemological standpoint, this study set out to determine how individuals with long term health conditions utilised online health information in their health decision making. To satisfy this aim, open-ended semi-structured format questions were utilised, with questions omitted, added, adapted and elaborated according to each participant response. To promote two-way dialogue and rapport between the researcher and participant, the researcher framed questions within conversation rather than using a directive tone, in order to better explore in depth central themes (Shaffir & Stebbins, 1990).

Given that the data was not coded into an existing framework, and considering the epistemological standpoint of this research, data was subject to inductive or “bottom up” analysis to ensure all identified themes were data-driven (Patton, 1990). The themes were identified at a semantic/latent level (Boyatzis, 1998), with the analysis process involving interpretation in theorising and determining the significance and meanings of these patterns in relation to previous literature as cited in the introduction (Patton, 1990).

### **3.2.2 Participants and recruitment**

Participants responded to the study recruitment notice circulated via internal (Health and Life Sciences) and external (e.g. Diabetes UK) email distribution lists (see appendix 9.1 for recruitment advertisement). Participants were also recruited from the university research participation pool. Through purposeful sampling, 15 volunteers (13 females, 2 males) with a mean age of 33.53 years (age range 18 – 66 years) from the United Kingdom participated in a two stage qualitative study. Participants had experience of 5 focal health conditions as described in Table 3.1. These issues were chosen to represent a range of long term and stage of life health conditions, as they were considered likely to represent a multitude of decision types, from treatment and procedural to management decisions. For example, this thesis presents pregnancy as a stage of life health condition as it does not fit the criteria for a short term or long term health condition (as described in section 3.1), but requires multiple decisions, monitoring and health management for a time period

(the latest date for pregnancy induction is 42 weeks as per NHS guidance). A multitude of literature has also considered pregnancy in health decision making literature (Lagan, Sinclair, & George Kernohan, 2010; Lagan, Sinclair, & Kernohan, 2011), such as unwanted pregnancy and abortion (Bracken, Klerman, & Bracken, 1978), pregnancy diet (Pullon et al., 2018) birthplace (Coxon, Chisholm, Malouf, Rowe, & Hollowell, 2017; Murray-Davis, McDonald, Rietsma, Coubrough, & Hutton, 2014), and foetal abnormality testing (France et al., 2011).

**Table 3.1.** Breakdown of participants health conditions.

<b>Health condition</b>	<b>Description/comments</b>	<b>Total number of participants (N=15)</b>
Pregnancy (stage of life)	2 participants were pregnant for the first time, 1 participant had one previous miscarriage, and 1 participant was having her second child	4 female (Participants: 2, 4, 9, 12)
Digestive Health Conditions	2 Participants had Ulcerative Colitis, 1 had Crohn's disease, and the remaining 3 had Irritable Bowel Syndrome (IBS)	4 female, 2 male (Participants: 1, 3, 5, 7, 11, 15)
Hormone Conditions	1 Participant had Hypothyroidism, 1 Participant had Polycystic Ovary Syndrome (PCOS), 1 Participant had Type 2 diabetes	3 female (Participants: 10, 13, 14)
Skin Condition	1 Participant had Eczema	1 female (Participant 8)
Autoimmune Disorder	1 Participant had Secondary Sjögren's syndrome* in conjunction with Rheumatoid Arthritis	1 female (Participant 6)

\* *Secondary Sjögren's syndrome occurs in conjunction with autoimmune conditions such as Rheumatoid arthritis*

All participants satisfied predetermined inclusion criteria, that they were aged over 18, with a diagnosed long term or time of life health condition, and have searched the internet for health information related to this condition to aid decision making.

Participants were remunerated £10.00 cash to compensate for their time and travel to the laboratory on the day of the interview. First and second year undergraduates signed up to the study via Northumbria University's electronic participation pool and were awarded 2 participation points.

### **3.2.3 Materials**

Prior to interviews participants completed a “Health Complaint” document (appendix 9.2) detailing their use of the internet for information sourcing about their health condition. This helped confirm participant eligibility but was primarily used to develop contextual detail for the interviews.

The interview was recorded using a Dictaphone for transcription purposes. A semi-structured interview guide (appendix 9.3) was developed and informed by the literature discussed in the introduction. The interview schedule was designed to explore how participants used online health information to help make decisions about their own health. For example, participants were asked how online information sources aided with their health decisions and whether they have discussed online sourced information with health professionals.

### **3.2.4 Procedure**

This study received ethical approval from Northumbria University’s Faculty of Health and Life Sciences postgraduate ethics committee prior to the interviews taking place.

Interviews took place over a two month period between February and March 2016. Fourteen face-to-face interviews were conducted at Northumbria University, and 1 conducted via Skype Call. Prior to the interview, participants were provided with an information document and signed a consent form upon confirmation of eligibility (see appendix 9.4 for study information, consent and debrief forms). Participants were informed about the confidentiality procedures in place, how their data was to be used and that they were free to withdraw from the study at any time without explanation. Participants were reminded they were not obliged to answer questions they did not wish to and that they could take a break by alerting the researcher. Once participants provided demographic information the interview and audio recording was started. Interviews lasted between 31 and 90 minutes. On completion of the interviews, participants were debriefed and thanked for their participation. To assure anonymity participant names were replaced with an identifying number, and in the transcription phase all identifying data were removed.

### **3.2.5 Procedure for analysis**

According to Attride-Stirling (2001), it is essential that psychologists are transparent in their analysis procedures; otherwise, difficulty ensues in evaluating and comparing the

research with other studies. To address this concern, the present research details the data analysis process, guided by Braun and Clarke's (2006) proposed phases of thematic analysis.

Data collected from interviews were transcribed verbatim (an example of a transcribed interview can be found in appendix 9.5). The researcher re-listened to interviews and re-read transcripts to confirm transcription accuracy, participant anonymity and to achieve data familiarity (Braun & Clarke, 2006). Throughout this phase, participant notes were compiled after each interview, which describe key messages as well as any interesting or novel narratives (appendix 9.6). The second analysis phase was identifying initial codes in the data that were organised into meaningful groups by code. As suggested by Braun and Clarke (2006), the researcher coded for as many potential patterns as possible, though many were not carried forward into the searching for themes phase, it is likely that some codes will be useful at a later date, potentially useful for drawing comparisons with the next study data (Study 2 of the research programme). The researcher then refocused the analysis at a broader level, searching for themes that help answer questions that were asked of the data (an example of the coding process can be found in appendix 9.7). Refining the themes produced in phase 3 included re-reading codes within each theme to ensure they formed a coherent pattern. At this point, some codes were identified as fitting some other themes better and were moved accordingly. Alternatively, some codes were discarded as they did not fit with the rest of the coded extracts. Then, each theme was reconsidered in relation to the entire data set to help further clarify the story being told. This final analysis was performed on a consensus reached by the researcher and project supervisor. Phase five included naming and defining the themes, to capture the essence of each theme and how it fits within the story the data is telling. Some themes were identified as containing sub themes, which were related to one another yet separable. Each theme was then appropriately named, to capture the essence of coded extracts.

### **3.3 Results**

Overall, participants discussed their need to be involved in their healthcare decisions and described how conversations with friends, family, HCPs, and internet-sourced information informed their health decisions. Participants described consulting a number of health websites for their health information and decision making needs. Notably, discussions tended to focus on the use of social websites where anecdotal information is shared and discussed, such as Facebook and personal blogs and websites authored by

people with a lived experience of a long term health complaint. Participants were motivated to consult online health information for many reasons, including to update their knowledge about their condition, to obtain different opinions, and to corroborate information provided by their HCP. Ultimately, internet resources supported decision making in a number of different ways, at different time points and in conjunction with other information resources.

In describing the ways in which participants' used online health information to help with health decision making, data presented around two themes. Within the first theme, "*Empowering processes*" data presented around two subthemes of "knowledge" and "support" as participants' described how use of online health information informed their knowledge and helped them feel supported in their health decision making. Two subthemes "supporting decisions" and "information integration and negotiation" also contributed to the second theme "*Integrated decision making*", as participants discussed how the empowering processes enabled participants to use the resources to support their decision making through discussion with a health professional and or other stakeholders, or directly in the absence of an HCP

### **3.3.1 Empowering processes**

Participants described two main ways in which online health information empowered them to become more active stakeholders in their own healthcare generally and specifically in their subsequent decision making. The first was about gaining knowledge and a better understanding about the decision itself the process, experience and the outcomes. The second was about feeling supported and reducing the sense of isolation about the condition.

#### *Knowledge*

For many, learning of others' health experiences helped them to contemplate potential changes and decisions that they too could make. In particular, learning about the processes and outcomes of other people's experiences in making a specific decision helped participants evaluate whether they would benefit from making that decision. Seeing how others have carried out the decisions provided the participants with first-hand experience. Participants were able to relate to the information and the author and apply the knowledge to their health decision making as discussed by participants 1, 7 and 14 below.

*I like using Imagur and Reddit and stuff and that's quite useful because you know its real people talking and experiences its sort of most of the time its similar experiences*

*to you so you can put yourself in the context of them and if they say “Oh this is really useful” you can be like “oh I’ll try that” (P1, female, IBS)*

*I just don’t think he (the GP) had experienced it himself so he couldn’t give much advice on it so and because there’s not a lot of, they don’t know themselves the GPs how to treat it, so getting the advice from people who are experiencing it on a day to day basis was like more value to me erm, because they could like offer credible advice like things that worked for them that the GP couldn’t because he hasn’t experienced it himself (P7, female, IBS)*

*I wanted to know more about the drug itself rather than the people who had taken it- and what their experiences were. Did it work? What were the side effects and what was it like when they came off? Erm cause coming off the drug is probably the most worrying thing (P14, female, PCOS)*

Online health information was thus useful in providing participants with information regarding the processes, experiences and outcomes of making different decisions. Though most talk focused upon treatment decisions, some participants also discussed their use of more social websites such as Mumsnet and e-commerce sites like Amazon to aid with health related product decisions. Products were sought to help alleviate everyday struggles associated with health issues (Participants 6 and 2) and to support health decisions (Participant 4 and 8).

*Equipment, that’s the other thing I’ve been looking about, stool things like that.... I could get one free on the NHS but it doesn’t fit in my kitchen so I discovered when I went for a massage that the the centre of my massage therapist and I was telling her about my difficulties and she said well what I’m sitting on might help you so that was, I did then go online ‘cause she got hers online (P6, female, Sjögren's syndrome)*

*So, reading again other peoples experiences there’s actual reviews done specifically on the buggies on Mumsnet and stuff... one buggy I was looking at like the reviews it was saying that the bottom, again with reviewing I decided to go for a tandem but they were saying the underneath seat hits the curb so straight away that cleared it off and that was just off reviews that other people have put on and obviously I’ve trusted that information and its been knocked of the list straight away (P2, female, pregnancy)*

*Its more like sociable type websites so they’re still talking about like health and what to do and like I spent a whole evening the other week looking up how to take a baby’s temperature and what thermometer to buy and like that, I suppose is technically health information on web pages (P4, female, pregnancy)*

*We just typed into the internet like what sort of things cause eczema and what sort of things like help it and stuff, and erm, it was found that for example Aloe Vera like really helps skin, so I started taking that and then Aveeno cream that was like another thing - that's supposed to really help and that's what I'm using at the moment (P8, female, eczema)*

These discussions support the idea that that health decision making does not always transpire as a treatment decision made in the confines of a medical appointment. Rather, the participants show that online health information is used to inform product purchases and treatment decisions independently in their own environment.

Participants also described how reading information on social forums brought to their attention a number of decisions that needed to be made. Their knowledge was further informed by the learning of new ideas, options and decisions of which they were previously unaware, including different treatments and methods of dealing with their condition.

*But it was the support thing like, and the treatment options really like different ideas and stuff of like how to tackle the illness (P7, female, IBS)*

*Oh absolutely loads, different vitamins people have tried erm exercises erm, different recipes there was this erm this man from America he'd put a website together and saying that he had Ulcerative Colitis he'd been on tablets for years... but he didn't wanna take tablets so he put together some vitamins he would take and like a food plan and he'd post it online... and it was just finding out like about the different kind of things (P11, female, ulcerative colitis)*

### *Support*

The second main way in which participants felt empowered to take a more active role in their healthcare was through feeling supported by the online community. Some participants reported actively contributing to discussions on social media, whilst others assumed a more passive, anonymous role by reading but not responding to information (lurking). Thus, participants felt less lonely and anxious, and more socially supported when reading encouraging stories and messages exchanged between other online users. For example, participants described how uplifting, positive discussions helped them feel better about themselves, instilling them with the confidence that they weren't alone, and that their experiences were not unusual, fostering an increased sense of belonging, familiarity, and social support.

*I think if I'm having a bit of a shit day like if I feel a bit eugh, that's when I might go on a forum and have a read see uplifting comments things like that (P14, female, PCOS)*

*I was looking at like IBS forums, subreddits which had like IBS talks and stuff and so that sort of stuff was quite useful because it makes you think, you know if you're having a symptom and turns out multiple other people are having the same symptom you're like okay its not weird its not something I should be rushing to the doctors for (P1, female, IBS)*

*It does like it does bring you all together and you know that you're not alone basically (P7, female, IBS)*

*I found it really useful cause you do thing god am I the only person who's got this I don't know anybody else who's got it (P11, female, ulcerative colitis)*

*I don't even know why I go to the forums I think it just makes me feel better that I'm not the only one in the boat but er there's not really any advice from people because it's like a hopeless condition that you're just stuck with forever (P13, female, PCOS)*

Reading or discussing other people's health experiences online, helped participants feel supported and not alone in their health decision making. For example, learning of the outcomes making a certain decision, helped participants to imagine themselves making that choice, and consider the implications of that decision.

Participants expressed feelings of empathy when reading about others' experiences, particularly when others described a more serious or severe situation. Making downward social comparisons contributed to participants feeling that they should be grateful for the position they are in, encouraging them to take a more active role in their health care. Therefore, by putting their own situation into perspective, participants fostered feelings of empowerment and described feeling less helpless but more content and motivated to actively participate in their own health in order to improve or stabilise their condition, to prevent deterioration.

*That is that is helpful even though you might not take peoples advice but reading that somebody else is having the same thing and how they've dealt with it sometimes you go well actually I'm doing a lot better with it so that's quite a good feeling (P10, female, type 2 diabetes)*

*I have searched like the emotional impacts of having acne and stuff I've googled that erm and just like people being upset but the thing is though I have to remind myself that I don't have the worst case scenario and I think that's something else I've googled, like people who've got more severe put it in perspective (P14, female, PCOS)*

*Yeah I think its erm made us more aware of what people go through, I know what I've gone through but like other people who've got it far worse who maybe have a bag on or they're out of hospital all the time and things like that (P11, female, ulcerative colitis)*

*And there's not much new you can really hear but as awful as it sounds sometimes when I feel like I'm having a bad day and I read someone's who has had a horrendous month year whatever, you sit there and go actually I'm not that bad off (P15, male, ulcerative colitis)*

When reading of others' lived experiences, participants 1, 2, 7, 10 and 12 described feeling reassured seeing individuals who had once been in a similar position were now supporting others, this helped participants realize that their problems were not unique, nor were they alone. Ultimately, this reduced feelings of anxiety and helped participants feel less isolated.

*Yeah definitely its more to do with like making sure that my experiences aren't abnormal cause if it was that would more encourage me to go to the doctors, erm, but otherwise it more just for like piece of mind, making sure I'm doing the right thing (P1, female, IBS)*

*I think it's nice to know as well that someone else has been in that situation before, and it's reassuring (P2, female, pregnancy)*

*Yeah like, although I got the main gist of what the illness was and the symptoms and treatments on the NHS website, I don't think it would have offered the support like thing, erm, just knowing that other people were sharing the same experiences as I had was comforting... if you go on forums and stuff and they're like it sounds like IBS and all symptoms are the same, like that's reassuring (P7, female, IBS)*

*You know within minutes people were putting a couple of messages coming up so it was quite good that in itself is reassuring cause you think well actually I'm not the only one who has this so yeah that was really really helpful (P10, female type 2 diabetes)*

*I think online searching makes my decision making more easier and it relaxes me because otherwise if I didn't know what would happen I worry because my family is not here and I have a few friends here, if I feel alone I would worry definitely (P12, female, pregnancy)*

In summary, online health information improved participants' health knowledge by highlighting the decisions that needed to be made and providing options and ideas. Engaging with other patient stories enabled participants to learn first-hand, the processes, experience, and outcomes of a certain health decisions, which they could then consider in their own decision making. Engaging with online health information, in particular other patient narratives, enabled participants to feel less lonely and encouraged them to become more engaged in their healthcare via social comparisons. Overall, the 'Empowering processes' theme demonstrates that online health information provided the participants with new knowledge and social support, which helped them feel able to make or take part in health decisions.

### **3.3.2 Integrated decision making**

This second theme describes how the empowering processes enabled participants to use the resources to support their decision making through discussion with a HCP and or other stakeholders, or directly in the absence of an HCP. Here the empowerment is translated into decision making with decisions being revised, returned to and made across certain time frames and involving different stakeholders. The ways in which participants use the online health information to support their decision making varies. In some cases, the resources are integrated into discussions with their HCPs, in others they prompt decisions to be made and for some people they act as a support to ongoing decisions (with or without HCP involvement).

#### *Supporting decisions*

Participants described how the online health information helped with decisions that were ongoing or still under review. These decisions often related to medication changes but sometimes concerned a single, one-off decision that had to be made. In these cases, the initial decision may have been made with the HCP or involved the HCP in some capacity but the online health information was clearly seen to be involved in the thinking around the decision – providing additional resources to the decision making process. In the three extracts below, the participants describe the ways in which the online health information

informed and provided support to ongoing decisions through both tangible information and the provision of alternative opinions and support.

*If you go back to like the drugs thing, like taking Membeverine I probably would have thought that like I just need to keep taking it regardless whereas knowing that someone else, and knowing that not just somebody else but multiple other people have said it didn't help them it made no difference, I know I can be in confidence and be like okay, lets leave it, lets move away from that it doesn't work (P1, female, IBS)*

*I was googling like what supplements and herbs I can take to try and balance my hormones and suppress my antigens naturally, erm so I was researching about spearmint tea, about licorice, erm eating flaxseed to boost your oestrogen levels so that stemmed to like sort of trying to control things through diet and lifestyle ... I'm literally taking zinc, erm b vitamins, vitamin d, erm I'm taking a grapeseed extract, erm I take chlorella, I take protein powder, this is like every single day, erm all to try and like just make us clearer (P14, female, PCOS)*

*I have a support networks of people that have almost helped me come to that decision and I hugely respect woman who do because a lot of them have been through the works in terms of pregnancy, you know some of them had twins, some have had multiple miscarriages, some of them have had babies that have been born with disabilities you know so there's a wide range of people that really help open your mind a little bit to the different type options you have and help make you come to a good decision I guess (P9, female, pregnancy)*

From the extracts it is clear that the online health information for some people had a direct effect on the decision whilst for others, the value of the information is acknowledged even if the decision may be something that technically occurs at a later date or in a different place. Participant 9 for example describes the way the online group ‘*have almost helped me come to that decision*’ – presumably the ‘final’ decision will have to be made in the presence of an HCP. Likewise reading about the experiences of others who have had a surgical procedure were useful for P15 in supporting his decision to undertake the procedure himself. Interestingly, P15 explains that the online health information doesn't ‘form’ his decision but it does support his decision making:

*So that's why when I do look at their experiences it does form me decision it just kinds of like no, help support it if that makes sense? ... And to an extent that has changed my views a little bit because it's not just this butchery where you have to*

*recover for months and you're just left and so seeing more success things online particularly with people my age erm, would be most beneficial for me I think erm to make decisions (P15, male, ulcerative colitis)*

The above extracts demonstrate how participants have considered and acted upon online health information, and ultimately integrated it into their decision making process. Participants also relied upon online health information to inform purchasing of products to support or improve their health condition. Specifically, participants discussed how patient narratives that described the process, experience, and outcome of making a certain decision, were key to supporting their health decisions. Once again, the extracts below demonstrate that the decision itself has already been made and that the online health information can act as a support, confirming a decision or helping the individual to evaluate the decision made.

*Needing a double buggy, I done sort of extensive research on the different types then whittled it down, and then I used, again, it's as simple as, I typed the two sort of, I got it down to two products typed them in, again on these mums review sites erm, people are reviewing the two buggies next to each other. So, reading again other peoples experiences there's actual reviews done specifically on the buggies on mums net and stuff, that helped us with my decision as well as going into \*High Street Store\* and trying them out for yourself, so it kind of backed up why its goanna be good for me and my life and my family sort of thing (P2, female, pregnancy)*

*Well generally if they come up, if it's about equipment or something like that it can be useful if people say "I use a size 16 for this... but then went to 14 because of so and so" and if that fitted my situation I might consider it (P6, female, Sjögren's syndrome)*

*So that definitely influenced my decision because that day I hadn't felt anything for a few hours I thought first of all don't panic, I know this website is a charity website and its erm, supported by doctors and midwives, I went there first took their advice first and then I still hasn't felt any movement that's when I thought no this isn't right I have to ring my midwife and she actually agreed yeah you've done the right things so you need to come on in and they had given me a scan and everything so definitely that website erm, helped me make a huge decisions because fetal movement almost becomes more important than heartbeat after a certain point (P9, female, pregnancy)*

*I looked on NHS choices then I went on forums and erm, they were saying the same things and I was like it seems to be pretty common, erm, and then like I decided to*

*book an appointment with my GP... he actually took some blood tests I think to see if it was a wheat intolerance or anything like that and nothing came up (P7, female, IBS)*

These extracts reflect how online health information may contribute additional detail or provide context to a decision that has already been made. This presents an alternative timeline to the decision making process, in that information searching doesn't always precede a decision, but rather that information searching may follow a partially formed decision, for example to evaluate the potential outcomes before making the final decision. In summary, the extracts highlight that information may be integrated at any stage in the decision making process, showcasing decision making is an iterative process.

#### *Information Integration and Negotiation with the HCP*

So far, the examples of integrated decision making have highlighted how the online health information can support people to realise there are decisions to be made, prompt action and initiate their decisions with the HCP. The focus thus far has been on the decision making activities that occur away from the consulting room, even if the participant ultimately has to visit the HCP for ratification or enactment of the decision. However, participants also described the ways in which they brought online health information into their discussions with HCPs, and how this supported their decision making in different ways.

Through engaging with online health information, participants described increased knowledge of their condition, and felt well versed to articulate and participate in conversations with their HCP. Participants felt empowered to integrate learned online health information into conversations with their HCP and felt more confident in their ability to do so.

Participants discussed how sourcing health information online contributed to them becoming an expert patient. Through increasing knowledge of their health condition and becoming wise to a multitude of treatments, choices, and patient experiences online, participants felt more confident to engage in collaborative discussions with health professionals at appointments. Participants described being better equipped to ask questions to elicit more information for HCPs, and to consider decisions and choices at the consultation.

In particular, sourcing and reading online health information in preparation for a consultation was common. For example, P9 described using online health information to

pre-empt the HCP's suggestions so that good decisions can be made by considering this information over a longer time period.

*Cause you know you can go into an appointment and be very overwhelmed with information that you almost forget to ask your questions... I actually wrote down questions that I wanted to ask them based on the kind of other things to sort of expect at that stage I was at from looking online... So it helped me kind of prepare for my appointments, not structure them, but just make sure I was a bit more prepared because like I say there very overwhelming... But a lot of it is for reassurance and helping me form a good decision based on all the options and stuff like that (P9, female, pregnancy)*

Similarly, P1 describes the way in which she already made a preliminary decision regarding her diagnosis although importantly she was open to other suggestions.

*It was more me coming in, me already knowing my symptoms pretty well, and able to like fully express my symptoms and say this is what's wrong and this is what I think it is, but I'm not sure it could be something else and when I was talking to the doctor, he agreed with my mum having IBS that it was probably IBS (P1, female, IBS)*

Becoming familiar with the potential options that might be offered to them meant that participants could consider these choices both before and during the HCP appointment, giving ample opportunity to raise any queries or concerns with the HCP. Generally, the consensus (as exemplified by P14 below) was that participants simply wanted to be on a similar level of understanding as the HCP thus putting themselves in a better position to be involved in decisions and challenge the HCP where they felt necessary.

*I already knew what she was gonna say cause I already researched it all, and I felt quite good and happy that I had read that myself... because I understood it more than what the doctor was giving us erm, cause I think if the doctor just explained and I didn't have that knowledge myself, I'd have went oh I dunno what that means it would have been harder to take in or understand... if I hadn't have done that research beforehand I'd have probably went what what do you mean like, is there a different type, like what? (P14, female, PCOS)*

Participants described occasions where they integrated the online sourced information into the appointment with the HCP. The excerpts below highlight occasions of successful integration with P8 describing how she searched online with her GP, looking at the

information together, and P9 describing how her improved knowledge assisted with discussions with a HCP.

*I think so because it like, when I mention stuff it like triggered her to like say stuff and like, my GP at home is really good so when I said stuff she went online and like researched it with me sort of thing (P8, female, eczema)*

*I actually find that the more information I knew before I called the midwife the more they respect you, so because they almost think they're talking to someone on a level playing field they can take you a lot more seriously than someone who doesn't quite know what they're talking about (P9, female, pregnancy)*

Being an 'informed patient' enabled the integration of knowledge into the appointment and seemed to have had a positive effect on the consultation, as participants describe flowing, mutually respectful conversations with their HCP. Online searching prior to the appointment was also thought to improve the pace of the consultation, assisting a quicker diagnosis and reaching mutually agreed decisions faster than if the HCP needed to explain a large amount of information in detail. For example:

*I'd say that it got me a quicker diagnosis than if I left it all up to them (the GP) because it was my mum insisting like can we at least test for this... you're going in with a couple of ideas what it can be might help narrow everything down and speed up the process (P3, male, Crohn's disease)*

*When I like got my information and was like I've got these symptoms, I've seen on the internet it looks like IBS, he was like alright then, he didn't ignore what I said he build on from that, he said I'll give you a blood test for this and this to see if you've got intolerances and so I think it probably benefitted him because it was like shortcut like find out what was wrong. If I went in and said I've got pains in my stomach he'd have to ask more questions and be more in depth (P7, female, IBS)*

However not all participants had positive experiences integrating online health information into the consultation room. Participant 15 described an occasion where the relationship and consultation was compromised due to the HCP's negative reaction to the attempt to introduce online health information into the discussion.

*Yeah so it was just like that he was like well nah it's probably best we just stick with this cause you're already on this I was like right okay well and you just kind of agree with them because some of them just don't involve you much in erm like*

*the decisions and stuff ..., I didn't feel as comfortable with him the next time in all honesty (P15, male, ulcerative colitis)*

In fact, many participants often commented on the importance of the HCP's reaction to a patient bringing online information into the appointment, as highlighted by participants 5, 6, 15 in the extracts below. This brings into question potential discordance between the expectations of the patients and health professionals within appointments and consultations. Possibly, patients are already aware of HCPs concern and are subsequently apprehensive in their attempts to integrate the online sourced health information.

*The doctor was okay with that, took that on board that kinda thing, it does very much depend on A, the person, and B the doctors response. Because if you're gonna go into a doctors surgery and say oh well I've looked this up online and bla bla bla and he says (inaudible) and dismisses it, then you know... whereas if he takes it on board and you know, perhaps it might help in the healing process I dunno (P5, female, IBS)*

*I have to be really careful how I do it depending on who it is... Professor \*\*\*\*\* is in research for Sjögren's and he's open to everything he wants you to write things down before you see him and he wants to know if you're ill and my GP didn't let him know when I was ill and I said to her I was about to, she said you don't need to because your inflammatory markers aren't up, but actually he told me two weeks before at a meeting that people whose inflammatory markers aren't up and have got erm fatigue have worse symptoms than those with inflammatory markers up and no fatigue if I'm making sense?... now she didn't take kindly to that she said well that's what I've been told and I'm not going to refer you, when I got to see him six weeks later he said well I really needed to have seen you then (P6, female, Sjögren's syndrome)*

*So I thought I'll show him and he was just like no no I prefer to stick with this cause its more I wanna say manageable and er but yeah... He just kind of criticized the research but I mean yeah I did that anyway cause a lot of the research is being doing in mice and rats and stuff erm which is kind of interesting but erm... he kind of took it on board but then at the same time you know when you can tell it's not gonna change someone's mind (P15, male, ulcerative colitis)*

In summary, within this second theme 'Integrated decision making', participants described how feelings of empowerment were translated into decision making activities.

The online health information supported decision making within the consulting room but also away from direct HCP involvement. Participant experiences also highlighted the timeline of decision making activities and the way in which decisions made or initiated elsewhere were reinforced or supported over time and with input from online and offline resources.

### **3.4 Discussion**

The present study aimed to investigate how individuals with long term health conditions use internet sourced health information to inform health decisions. This research identified two main themes which describe how individuals with long term health conditions use the internet to support their health decision making. Firstly, participants discussed the ways that online health information improved their health knowledge and helped them to feel supported in their health decision making. Secondly, the aforementioned empowering processes enabled participants to make a number of health-related decisions without direct HCP intervention, but also gave participants the confidence to introduce and negotiate health information with their HCP where necessary.

The present study also highlights the role of empowerment in participants' health decisions. Participants described that online health information, in particular patient narratives, empowered them to make health decisions by improving their knowledge surrounding the health issue, and feeling socially supported. Participants highlighted that online health information alerted them to health decisions of which they were previously unaware and enabled them to gather knowledge on different options and health information, which they were then able to consider in their health decision making. These findings support the multiple decision making activities identified by Entwistle and Watt (2006), and provide evidence in support of the notion of DDM (Rapley, 2008), which emphasises the way in which a number of decision making activities can occur outside of the medical appointment itself.

Participants also discussed how reading patient experiences helped them feel less isolated and more socially supported in making a health decision. In particular, participants described how learning about patients' experiences and outcomes of making a decision was helpful in their equipment purchasing decisions and in consideration of surgical intervention (Participants 2, 6, & 15). Previously, patient narratives that include the process and experience of making a decision have been shown to impact hypothetical decision making (Shaffer, Hulsey, et al., 2013; Shaffer & Zikmund-Fisher, 2012), thus

the present findings demonstrate the use of these narratives to inform real life health decisions and support previous experimental findings.

The empowerment findings reported here speak to previous literature. For example, Buchanan and Coulson (2007) report that empowering outcomes such as ‘being better informed’ are likely to have occurred through improved knowledge obtained through peer support, and that users of OSGs may foster positive psychosocial outcomes including reduced sense of social isolation (Mo & Coulson, 2012). Also, van Uden-Kraan, Drossaert, Taal, Shaw, et al. (2008) and van Berkel et al. (2015) have identified the empowering processes of exchanging information and emotional support in OSGs. Therefore, the present findings contribute to knowledge by highlighting how these empowering processes exist in the broader context of online health information.

The integrated nature of decision making can be seen clearly in this study. Participants described using the internet to inform a number of health-related decisions, such as treatment, product purchases, and healthcare or service related decisions. Overall, participant discussions highlight the idea that online health information informs a multitude of health decisions which can occur outside the confines of a medical appointment. This finding reflects the integrated nature of health decision making and lends support to Rapley’s (2008) notion of DDM, as participants demonstrated how health decision making can be informed through interactions with other patients and facilitated by the use of technology. Interestingly, talk of specific decisions often emerged slowly through the interviews. Pinpointing how and when they had made a decision was something that participants found difficult to do and may reflect the notion that decisions form over a period of time and are transformed by new knowledge acquired from interactions and conversations with different people (Rapley, 2008).

Another key finding of the present study centres on the integration of online health information into the medical appointment. Although participants described how empowering processes such as improved knowledge and social support enabled a number of health decisions (e.g. treatment decisions, product purchases and care related decisions) without direct HCP intervention, these empowering processes also manifested in participants integrating and negotiating the information into discussions with their HCP. For example, participants reported searching online health information in order to arm themselves with knowledge to challenge the HCP’s perspective where appropriate. (Caiata-Zufferey et al., 2010). Secondly, participants reported using online health information to familiarise themselves with terminology related to their health conditions

in order to have a similar level of understanding as HCPs to support conversations with the HCP. The use of medical terminology by HCPs has been reported as a barrier to shared decision making (Bensing et al., 2011), as participants feel HCPs are “talking another language” (Nordgren & Fridlund, 2001) or “talk so far over patients’ heads” (Fraenkel & McGraw, 2007), sometimes leading patients to misinterpret the procedures being offered (Farahani, Sahragard, Carroll, & Mohammadi, 2011). Thus, the empowering process of knowledge acquirement supports the integration of online health information into the appointment by helping patients prepare and feel able to participate in conversations and health decision making with the HCP.

Participants in the current study reported their successes and failures to integrate online health information into appointments with an HCP. When successful, participants reported that their improved knowledge helped them articulate their health issues and improved the pace of the consultation, resulting in a quicker diagnosis. However unsuccessful examples acknowledged the importance of the HCP’s reaction to a patient bringing online information into the appointment as in previous research (Ahmad et al., 2006; Bylund et al., 2007). This finding hints toward the potential conflict in HCP’s and patients’ understanding regarding the integration of online health information into the appointment. Given the contemporary emphasis for patients to be involved in their healthcare, discordant perspectives may prevent participants integrating online health information into appointments, particularly if patients are aware of this.

### **3.4.1 Conclusion**

The findings reported in this chapter provide clear evidence in support of the integrated nature of decision making, as participants reported using online health information to inform a range of health decisions which occurred both within and outside of the medical appointment, and took place over a variety of time periods. Participants also reported obtaining knowledge and feeling supported in their health decision making from their online health information searching, these empowering processes helped people to feel supported in their decision making. Thirdly, participants described successful and unsuccessful integration of online health information into discussions with HCPs, which brought to light the potential discordance between HCP and patient.

### **3.4.2 Strengths and limitations**

Literature thus far has seldom considered how individuals with long term health conditions use online health information to support health decisions other than treatment

related decisions. The present findings are important as they demonstrate a number of decision making activities are involved in health decision making. In particular, this study is novel in its efforts to examine the use of the internet as a health resource as a decision support tool from a broader perspective. Fifteen participants may be considered a small sample size, however participants represented a broad range of long term health conditions and decision making activities. This ensured that the present study captured a more thorough understanding of how the internet is used to support decision making in individuals with chronic health conditions and their experiences.

### **3.5 Chapter summary**

This chapter described a qualitative study designed to explore how individuals with long term health conditions use online health information to inform health decisions. Taking a broader perspective on decision making has allowed the range of decisions and the more complex ways in which online health information supports decision making activities to be highlighted. Previous literature has tended to focus on how individuals with chronic health conditions use online health information to make treatment decisions and has seldom considered how online health information may be used to inform other health related decisions. The present study findings contribute to knowledge by demonstrating the existence of multiple health related decision making activities, highlighting the existence of empowering processes within the broader context of the internet as a health information resource, and provides support for the notion of DDM (Rapley, 2008).

These preliminary findings warrant further investigation, for example, it is important to also consider how individuals with short term conditions use online health information to support their health decisions, and identify any differences between these two groups (see Chapter 4), and also to consider whether the findings discussed here are representative of a broader sample (see Chapter 6). The next chapter (Chapter 4) describes a qualitative study that investigates how individuals with short term health complaints use online health information to inform health decisions, from a DDM perspective.

## **Chapter 4: The use of internet sourced health information for health decision making in individuals with short term health complaints (Study 2)**

The previous chapter investigated how individuals with long term health conditions search for and use online health information to inform health related decisions. The present chapter describes the findings of a qualitative investigation that aimed to address how individuals with short term health complaints use online health information to inform health related decisions. This group of people has received comparatively little attention in the research literature and this study aims to fill an evident gap by addressing how individuals with short term health complaints use the internet in respect to their decision making.

### **4.1 Introduction**

Previous literature well documents how individuals with long term health conditions use online health information to support their healthcare, including the use of online support groups (Bartlett & Coulson, 2011; Meade, Buchanan, & Coulson, 2017; Mo & Coulson, 2012; van der Eijk et al., 2013) and social media (Merolli, Gray, & Martin-Sanchez, 2013; Partridge, Gallagher, Freeman, & Gallagher, 2018). Information search behaviours have been explored qualitatively (Lee, Hoti, Hughes, & Emmerton, 2014a) and experimentally (Shaffer, Owens, et al., 2013; Sillence et al., 2014), and information search interventions to improve credible information sourcing singularly target chronic health information seekers (Lee, Hoti, Hughes, & Emmerton, 2014b). In comparison, research has seldom investigated how individuals with short term health complaints use online health information to inform their health related decisions. As described in Chapter 3, a long term health condition can be considered as a condition that may not be cured, is often managed and maintained, and can have a large impact on life quality (Institute for Public Policy Research, 2014). For the purpose of this thesis, a short term health condition is conceptualised as a health complaint that is short in endurance and where a treatment may (for some issues) be offered to resolve the complaint.

The abundance of literature documenting the role of online health information in chronic healthcare, may be attributable to the mass of published health messages that often encourage condition-management, medicinal compliance and adherence, as increased condition knowledge reduces healthcare costs (Colombara, Martinato, Girardin, & Gregori, 2015). It is likely that these messages have informed a considerable proportion

of research investigations into the use of online resources in individuals with chronic health conditions. While short term conditions and complaints may present less complex decisions and fewer compliance issues, the cost of minor ailments and acute health issues is worth acknowledging. These costs include the impact on waiting times in doctors' surgeries and accident and emergency departments, which are reflected in a recent NHS England report that shows a reduction in the percentage of accident and emergency attendees seen within the target time of four hours (NHS England, 2019). Despite the pressures imposed by both long and short term health complaints, research is yet to address how people with short term health complaints use online health information to inform their health decisions.

In addition to the lack of research considering the use of online health resources in acute healthcare, the literature also fails to represent how this information informs a multitude of health decisions (e.g. deciding to consult a certain information source, deciding whether to make an appointment with a GP), but rather concentrates on how different information types (static and narrative) influence treatment decisions (Vikki Ann Entwistle et al., 2011; France et al., 2011; Lagan et al., 2010; Shaffer, Hulsey, et al., 2013; van Berkel et al., 2015; Ziebland & Herxheimer, 2008). Chapter 3 therefore addressed how individuals with long term health conditions use online health information to inform a wide range of health related decisions and provides evidence for the notion of DDM (Rapley, 2008). This concept proposes that health decisions can be transformed over time and changed through interactions with multiple technologies and individuals. For instance, participants described using online health resources to support various health related decisions and activities including; trying home remedies, making lifestyle changes, using OSGs for information gathering, case building, and social support. The treatment decisions represented in the majority of published work also typically follow an encounter with a HCP, though this is not always the case. Some participants in Chapter 3 reported that online health information empowered and assisted them to make a health decision without HCP intervention.

## **Rationale**

Whilst Chapter 3 contributed to knowledge by addressing how individuals with long term health conditions use online health information to inform health related decisions, the literature base still fails to represent individuals who use the internet to inform short term health related decisions. The current study therefore aims to investigate how individuals

with short term health complaints have used online health information to assist them with a related health decision. This study seeks to extend findings reported in Chapter 3, therefore differences in internet use will be highlighted and discussed where appropriate in the discussion section.

## 4.2 Method

### 4.2.1 Analysis approach

The current study adopted the same approach as described in Chapter 3 (section 3.2.1).

### 4.2.2 Participants and recruitment

A purposeful sampling method was used to recruit 22 volunteers (6 males, 16 females) from the North East of England. Participants ( $M = 25.75$  years, age range 18-50 years) were required to be at least 18 years old, had experience of a short term health complaint, and had consulted online health information to assist them with a health decision related to this complaint. Participants were recruited via Northumbria University's electronic participation pool and campus wide poster advertisements. First and second year undergraduates volunteered via Northumbria University's electronic participation pool and were awarded 2 participation points. Other participants were not compensated for taking part.

Participants had experienced a wide range of short term health conditions as described in Table 4.1. These conditions incorporated numerous decision types, from treatment to procedural decisions.

**Table 4.1.** Breakdown of participants health complaints

Participant Number	Age	Gender	Health Complaint
16	30	Female	Mole query and weight gain
17	24	Female	Leg pains
18	DND	Female	Uterine fibroid embolization (UFE)*
19	29	Female	Sore throat, fever and cough
20	48	Female	Breast discomfort, heart palpitations
21	27	Male	Stomach pain
22	18	Female	Migraine, rash
23	33	Female	Rash

Table 4.1. continued

<b>24</b>	<b>23</b>	<b>Male</b>	<b>Common cold symptoms, diet and exercise training supplements</b>
<b>25</b>	20	Female	Chest infection, verruca, contraceptive pill side effects
<b>26</b>	20	Male	Eczema (flare up)
<b>27</b>	18	Female	Tonsillitis, Meningitis endometriosis
<b>28</b>	18	Female	Flu
<b>29</b>	20	Female	Meningitis, anaemia
<b>30</b>	18	Female	Cystitis
<b>31</b>	20	Female	Conjunctivitis, tonsillitis
<b>32</b>	50	Male	Muscular pain
<b>33</b>	21	Female	Anaemia,
<b>34</b>	34	Female	Sleep paralysis, vaccinations, headaches
<b>35</b>	21	Female	Cold/flu
<b>36</b>	DND	Male	Glute Pain
<b>37</b>	23	Male	Upset stomach/ stomach pain

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\* *UFE is a minimally invasive procedure to treat fibroid tumours of the uterus which can cause heavy menstrual bleeding, pain, and pressure on the bladder or bowel.*

### **4.2.3 Materials**

As per Study 1, prior to the interview participants completed a “Health Complaint” document which detailed their use of the internet for information sourcing regarding their short term health complaint. This helped confirm participant eligibility but was primarily used to develop contextual detail for the interviews.

All interviews were digitally recorded using an Olympus Dictaphone for transcription purposes. The semi-structured interview guide used in Chapter 3 was reviewed and adapted in order to suit the present study sample. As the underlying aims of Study 1 and 2 are similar (i.e. to investigate how individuals use and integrate online health information into health decisions) the interview guide did not differ drastically. The interview schedule was modified where appropriate to explore how participants used online health information to help make decisions about their own short term health conditions. For example, participants were asked how online information sources aided with their health decisions and whether they have discussed online sourced information with healthcare professionals. Thus, the interview guide remained relatively consistent

across studies, with most variability stemming from the researcher using the guide flexibly pursuing emergent issues where appropriate.

#### **4.2.4 Procedure**

This study received ethical approval from Northumbria University's Faculty of Health and Life Sciences postgraduate ethics committee prior to the interviews taking place.

Interviews took place over a one month period between June 2016 and July 2016. All interviews took place face-to-face with the researcher at Northumbria University in a quiet, private room. Prior to the interview participants completed consent documentation and were informed about the confidentiality procedures in place, how their data was to be used and that they were free to withdraw from the study at any time without explanation. The interview and audio recording started once the participant had provided demographic information and was comfortable. Interviews lasted between 26 and 50 minutes. Upon completion of the interview the audio recording was stopped and saved for later transcription. Participants were then debriefed, and participants were thanked for their participation. To assure anonymity participant names were replaced with an identifying number, and in the transcription phase all identifying data were removed.

#### **4.2.5 Procedure for analysis**

Transcribed interviews were thematically analysed following Braun and Clarke's (2006) proposed phases, as described in Chapter 3 (section 3.2.5). For examples of the analysis process see appendix 9.8.

### **4.3 Results**

Thematic analysis identified three themes. The first theme '*The internet as a triage device*' describes how participants with short term health complaints used online health information to help with the initial decision of whether or not to make an appointment with their HCP. In many cases using the internet in such a way lead to some participants '*Deciding to avoid the HCP*' in order to avoid burdening the very busy HCP. In the second theme '*Going solo: Making the decision alone*' participants described the ways online health information enabled and supported them to made health decisions independently, including altering prescribed medication or trying home remedies. The final theme '*Information negotiation and integration*' describes occasions where participants successfully and unsuccessfully integrated knowledge from their online research into a

medical appointment, and addresses how this affected the patient-professional relationship.

Together these themes capture the way in which the internet played a role in informing health decisions. The extent to which the internet provided a pivotal role varied. In some cases, participants used it as a single, stand-alone information resource and based their choices on this information only, e.g. changing medication or purchasing a certain product. In other cases, participants integrated the information into medical consultations and appointments that aided discourse with HCPs. Participants primarily recalled using factual information obtained from static information websites such as the NHS choices and WebMD to help them with their health decisions. The most common way in which the participants made use of the internet, however, was in deciding whether to seek medical help, the internet would present and suggest options they could explore independently, as well as proposing medical interventions.

#### **4.3.1 The internet as a triage device**

In many cases, participants would initiate their information sourcing by searching broad terminology in Google. Participants then explored their chosen websites from the search results, and this sometimes helped the participants recognise and identify they had some decisions to make of which they were previously unaware. One of the earliest decisions brought to participants attention, was to consider whether their health concern required medical intervention or assistance. This was a recurrent theme prominent throughout interviews, as participants described using the internet as a triage tool, helping them to decide whether or not their complaint justified making an appointment with an HCP. Many described the internet as a stepping stone to help with this decision, as Participant 21 explains “*it might just help enough that I don’t have to go*”.

*I have been diagnosed with a condition now, which is brilliant. The NHS website was spot on. Everything they said was the cause was the cause. If I had left that it could have been really fatal (P22, female, migraine, rash)*

In some cases, participants considered the severity of their complaint (is it life threatening?) before contemplating sourcing internet advice. The examples below describe two opposing actions, the first details an experience where the participant considered the online information acceptable to put into practice. The second describes how the information encouraged another participant to seek medical advice for an issue which had the potential to be serious.

*I'd decided that I wasn't going to seek outright medical advice for this particular complaint... It was a case it's not a life threatening thing. It's not going to put me in a wheelchair or anything like that. It's a pain. It's discomfort and I can deal with it in the short term while I try to see if this [online advice] works. (P36, male, glute pain)*

*I was quite busy. So I just put the doctors off and I was like, "Okay I'll just look online and then see if it sounds serious or not." Then I was like, "Yes this is quite bad and I can't sleep now. So I should probably go to the doctors. I don't think it is my anaemia just playing up." (P33, female, anaemia)*

Despite being a useful tool in helping people to decide whether further action is needed, online health information did induce worry in some participants, who as a result of their symptom searching believed they had a more sinister health issue. Like P33 described above, other participants also recalled consulting with a HCP as a precaution.

*I was getting some quite severe debilitating muscular pain to the extent that I couldn't walk up and down stairs properly and I couldn't pick things up... So I went online and started searching symptoms...I thought I've definitely got MS, this is a problem... So I did. I made an appointment to go up and see the doctor... It turns out that I didn't have MS at all (P32, male, muscle pain)*

*I was googling symptoms, erm, then, when it came up with "It could be this rare form of cancer", I went straight to the GP, I didn't, I didn't hang around (P20, female, breast discomfort)*

As expected, some participants acted upon the 'better to be safe than sorry' premise, only to find out they had nothing to worry about, or that their issue was not as serious as they had initially expected from their internet search. Participants who decided to seek medical assistance discussed how online health information helped them to prepare for the appointment, as presented in the following examples.

*I think everyone just feels a sense of reassurance if they look at it online before going in, so that they know what they're expecting maybe (P33, female, anaemia)*

*Erm, yeah, I definitely felt like it, erm, definitely helped me have a bit more of a clearer picture of, like, what was going on, and enabled me to be able to ask questions. Which I might not have been able to, erm, ask otherwise (P19, female, fever symptoms)*

*I try and read up and then at least, you know- I don't like going as it is, so I might as well go and do it properly, if that makes sense. Get it out the way, get it done instead of them going in kind of like, half arsed and then not really getting anything from it and end up going back (P21, male, stomach pain)*

For some participants, utilising online health information as a triage tool also served an additional purpose and helped them prepare for the appointment. Participants reported being better able to communicate their health concerns more clearly and efficiently with their HCP to optimise the appointment. Ultimately, this seemed to encourage collaboration with HCPs through informed discussions to help reach a shared decision, as described by P23 and P21:

*It was more like knowing all of my options cause you get like fifteen minutes or ten minutes um you need to make use of the ten minutes like you have and give them all the right information cause there could be a point during that discussion where the surgeon said to me which one of these things would you prefer to do and because I'd read up on it I was able to say yeah this but if I hadn't I would have to sit there and have everything explained to me again (P23, female, rash)*

*I think the more you know, the more you can actually talk about it properly. Erm, because a lot of times you can go to your GP and you're just kind of taking it at face value what, what they're saying. But if you've kind of looked up- I mean, if they say what the website says or something like that then it obviously will probably add kind of like added confirmation. Or you might feel a little more okay about it (P21, male, stomach pain)*

#### *Deciding to avoid the HCP*

In contrast, many participants discussed their preference to avoid consulting with a HCP completely. This subtheme contributed to the overarching “Internet as a triage device” theme as participant responses highlighted two main motivations for using the internet as a triage tool to do this.

Firstly, numerous participants described the NHS and HCPs as being “*pressurized*” (Participant 34), hailing the internet as their first “*port of call*” (Participant 19) when considering a health decision, to avoid unnecessarily burdening the healthcare system or professionals. This finding shows the internet fits into patient health decisions independent of discussion with HCPs.

*It's part of my upbringing with my mum and we did a lot of self-diagnosis when I was growing up. Also it's that old thing that you don't want to pester them with stuff you don't need to. If I don't need to go to the doctors I won't (P19, female, fever symptoms)*

*I just Googled the problem that I thought it was and I was able to get some quite good information off it without having to waste anybody's time or having to explain to every Dom- Tom, Dick and Harry that I've got a stomach pain... it was quite easy and accessible (P37, male, stomach pain)*

As highlighted by the excerpts above, many participants perceived their use of the internet in such ways to be beneficial to both themselves and the health professionals. Access to online health resources enabled participants to self-diagnose and make treatment decisions regarding minor ailments without burdening the care system or HCPs. Taking a slightly different angle, some participants described their online health searching to be driven by undesirable aspects surrounding medical consultations, such as limited appointment availability and time constraints imposed on consultations, as described below by P31. This suggests that some participants feel they had no other option but to search online.

*A lot of the time I think it's just easier to Google rather than wasting time trying to get an appointment at the doctors. And then realising that you didn't really need one because they'll just tell you what you could find online (P31, female, conjunctivitis, tonsillitis)*

*I suppose the online information gives you some time to really look at it because obviously, if you're in a room with a consultant, they've only got a finite amount of time to sit in that room with you. So at least if you can go over something online, it just gives you time to digest the information a little bit more and cross-reference well, what does that technical term actually mean? (P18, female, uterine arterial embolism)*

Irrespective of motivation, this sub theme highlights how participants utilised online resources as a triage tool, in order to minimise or totally avoid HCP contact. In this sense online health information played a central role in helping participants to make decisions about short term health complaints, owing to its attractive features such as being “fast” and “convenient” in comparison to making an appointment with a HCP.

### 4.3.2 Going solo: Making the decision alone

It was clear in the analysis that the internet has helped participants make health decisions without requiring input from HCPs. Online information was used to make lifestyle changes e.g. exercise or diet, as well more serious health related changes pertaining to medication dosages. P35 and P37 for example, described using the internet to resolve the health complaint without requiring medical intervention.

*Give the advice a chance and see how that worked. As I say, if it hadn't worked in two/three weeks, whatever it was, a month, then you'd go to the GP and you'd say, "Look, I didn't want to bother you with this. I've been trying different things and nothing is working." (P36, male, glute pain)*

*Erm, and obviously it's been quite successful. Like I say, I get- I still get stomach pains, but it's not on the scale of what it used to be. And if it did get worse without my diet getting worse, I think I would go and see a GP still (P37, male, stomach pain)*

Often participants did not make clear whether the information originated from a static website or from a collaborative knowledge sharing platform. Participants described acting upon the online information and recommendations to make preventative changes to lifestyle for example, to abate the issue rather seeking advice from a professional immediately.

*So sort of Googled what potential it could be, erm, like potential that it could be like, coeliac disease or anything like that. But, erm, before- they sort of advised before even going to see a doctor and stuff, change your diet... And then I looked on the website and it says with coeliac disease avoid, erm, sort of these types of foods. So I've just been doing that since and I haven't had half as many problems (P37, male, stomach pain)*

*I get this really sort of lumpy horrible red rash and I had narrowed it down to when I was like after I'd been out so I looked on the internet for like alcohol allergies and my exact rash just came up. And it was other things that can trigger it is caffeine and stress. So I was like okay, I can't stop drinking. I tried to stop drinking and it lasted two days, and then I had a glass of wine and I got a rash again... So I've cut down on all the things I can like coffee, there were another couple of things on there but they weren't relevant to me so I just kind of ignored them and I have cut down on alcohol, so I did kind of do a little bit about them but not as much as I should have done (P23, female, rash)*

In other cases, participants learned of home remedies as suggested by others who were or had previously been in the same or similar situation. The excerpts below highlight some occasions where participants were motivated to identify something that could be used to treat the issue or improve symptoms.

*So I was really tired and I kept getting colds um, so I just had a look for things that would help my immune system and stuff. I realised after reading about it that I probably wasn't getting enough vitamin c so I started reading about it and I've been taking vitamin tablets for the last few months (P23, female, rash)*

*one of them did say that you can try black masking tape on the verruca so and I had heard this off a friend who had one as well and because a lot of people on the discussion thread had mentioned that they used it and it had worked for them so I did give that a go and I think there was another suggestion that somebody had given but then a couple of comments down people were saying ah that didn't work for me so I did disregard that one so it was a consensus of which was the most popular remedy and then I did try it for myself (P25, female, verruca, contraceptive pill)*

*Er, yeah, like, erm, I would make, like, my own little concoctions of, like, whiskey and lemon, and, like, put, like, paracetamols, erm, in. And, erm, there was also, erm, I, like, googled, like, throat sprays and stuff. Because my throat was really sore. So, like, erm, I got information about all the different types of, like, throat sprays, and like which ones was, like, recommended, erm, for certain things (P19, female, fever symptoms)*

In many cases, online health information helped participants make decisions around treatment options for their health complaint. Participants described using the online advice to purchase treatments and remedies based on reviews and suggestions of others recommendations and experiences, thus the resource was narrative in content.

*Yeah so normally with the health with the dietary ones um, I will have searched what the recommended daily dose is and add it to my diet, it was quite recently omega 3 that I was searching but I don't eat things like fish and things like that and I started researching it and seeing how key it was in your biology so I started reading the information that I found and what I was researching and went and bought some omega 3 (P24, male, cold symptoms, exercise supplements)*

*Yeah, yeah, so I bought one (throat spray) based on, sort of, like, the, erm, the stuff that I'd been looking online (P19, female, fever symptoms)*

*I did with the migraine but I didn't with the rash because I found on a forum people were sending links to some creams. They were saying, "This is what you are going to get if you go to a doctor". I bought quite a few of them and it helps..... I clicked on the links and I just bought all three that were the main ones people were saying to get... I just thought, "It is worth a try to stop wasting time". (P22, female, migraine, rash)*

In one particular case, the participant could not recall where the product was purchased from; *"I'm not entirely sure how we found it... but I think it was just someone selling it on a website so I just looked up eczema herbal treatments or something like that"* (P27) this demonstrates lack of concern for the product quality and highlights an oversight which could have had serious consequences.

Another potentially harmful behaviour (described below by P19 and P21) encouraged by some of the online health information, was participants' readiness to stop or change prescribed treatments and alter dosages having searched for information about the medication online, without authorisation from a medical professional before doing so. Participant 19 describes doing this for her own health issues, whilst P21 discusses making this choice for a family member.

*Erm, yeah. I had this infection, and I went to a walk-in centre, and they prescribed me the correct medication, but a very, quite low, dosage. And when I'd gone online then, erm, I'd realised that I probably should have been on a double dosage... So I doubled my dose, and then went to my GP, erm, like, on the, the week after, and that was kind of based on the information that I'd got from, like, I think it was like the NHS website or something like that. Erm, so I did that again after I got my antibiotics for the tonsillitis. Erm, just to check. (P19, female, fever symptoms)*

*I mean, my dad got given, erm, his medication... but then we read through all the side effects and we were like, "You should probably not take them." And we decided to not take them and see if he can manage it normally. Because they were like really severe.... I was like, "You are not taking double." Like, because he has prepacked medication things, so I went in each one and put it back to half manually. Then told him, I was like, "You're going to do that now tomorrow.*

*You're going to- or whenever you get your appointment, you're gonna go and tell them you don't- why." (P21, male, stomach pain)*

The above excerpts show participants making adjustments to prescribed medication as advised by information from the internet. Sometimes, online treatments and remedies were tried as participants considered them to be non-serious, harmful or damaging.

*Yeah if its exercise stuff then you don't need like caffeine to live and- Yeah like if they said this caffeine product made me feel more energised then I might give it a try (P24, male, cold symptoms, exercise supplements)*

*I do tend to make quite a quick decision. If it was go out and take all these tablets from a chemist I'd probably not, unless I had professional medical advice or asking the chemist about it, but if it was natural things like the honey and lemon with the drinks and things like that, I'm quite happy to try that straight away because I know it's not going to affect me so much (P34, female, sleep paralysis, vaccinations, headaches)*

Though Participant 34 states that she wouldn't make changes to prescribed medication without consulting medical advice, the general consensus was that lifestyle changes and herbal remedies were worth trying as participants considered them to be harmless, or due to worsening symptoms, they became increasingly desperate for a cure and would be willing to try suggestions that had worked for others.

*It's not really usually that serious. It's usually just cold symptoms or flu, just to find out quicker ways to get rid of it than just waiting about (P35, female, flu symptoms)*

*Yes. I think anytime that I get it now; I can feel it coming on so I know when it's going to happen, I just think, "For God's sake I'd literally do anything just to get rid of it"... as soon as someone suggests it I'll try it, just because I've tried everything that I thought I knew. If I find something else, like someone said sitting in warm water and salt, as soon as I found something else I thought, "Oh my God if that works it will be so good." So I try everything (P30, female, cystitis)*

### **4.3.3 Information negotiation and integration**

This theme describes how online health information was often integrated into medical appointments, where participants would use their improved knowledge to negotiate the information with their HCP to collaboratively reach a mutual decision.

According to participants, consulting online health information prior to an appointment helps them to be better informed about their symptoms and potential diagnoses. Ultimately, this assisted participants in verbalising their complaints more eloquently and become more actively involved in the mutual discussion, as exemplified in the following extracts.

*I have to be massively involved with it and I think it's really important that everybody is but I suppose there is an education issue there as well... I think it's important to do all your homework and be able to articulate what's wrong I think that's a bit of an issue as well though cause if you read everything on the internet and get everything together it helps you understand how to describe it to the doctor sometimes and that can be really helpful and you can take their advice on board as well (P23, female, rash)*

*I definitely felt like it, erm, definitely helped me have a bit more of a clearer picture of, like, what was going on, and enabled me to be able to ask questions. Which I might not have been able to, erm, ask otherwise (P19, female, fever symptoms)*

*It is really good to go to your doctor informed because it stops them asking a million questions. You can go in and explain everything (P22, female, migraine, rash)*

Being more informed and well versed in articulating the health issues was considered advantageous as appointments were more efficient as a result. This reiterates the earlier discussed theme of participants wishing to avoid burdening the healthcare system.

*It is better to understand as well. Doctors, you can feel quite intimidated with all their jargon and language. Going in there I understood what she was saying and that sped it up way quicker. (P22, female, migraine, rash)*

*Makes it a lot quicker rather than going to the doctors and be like, "I don't know what's wrong with me. Can you help?" And then he'll be like looking all over and not knowing where the problem is, do you know what I mean? (P31, female, conjunctivitis, tonsillitis)*

Ultimately improved knowledge fostered from online searching, often led to more equal contributions in discussions with the HCP as patients felt more confident to voice their

concerns, perspectives, and ideas. Participants P18 and 19 give an example of specific occasions where this was beneficial to the appointment.

*Well, it also, I think, probably generates more useful information in a two-way process as well because, you know, if you've got somebody who, you know, is just what seems to be the trouble, you're not really going to part as much information (P18, female, uterine arterial embolism)*

*I think, the, the amount of knowledge that I have about, erm, the illness that I have, for example. Erm, so, if, if I'd looked online and had quite a bit of information, I might be able to have more of, like, a 50/50 conversation with the, with the doctor (P19, female, fever symptoms)*

Participants talked about their experiences integrating what they had learned from their internet searching into appointments with their HCP. The examples below show times where participants openly discussed their internet searching, which was well received and often appreciated by the HCP.

*When I went in there I knew what all of my three options were - one of them wasn't an option but I didn't know that until I spoke to the doctor. But I read up on all three of the things that he could have possibly done and then when he says I'm going to do this and replace this with a plastic joint and do this - I was like right, I know, I've even watched it. So I was like so you'll do this, and this and this and this and I'll be in hospital for one day (P23, female, rash, when talking about a previous operation)*

*Yes, most of the time I'll probably go in like I'll say, "I've had this and I've looked online and I think it's conjunctivitis." And most of the time they'll be like. "Ah yes I think you're right it's just conjunctivitis." So most of the time it's a case of me knowing what's wrong or me going to the doctors and like, "This is what's wrong" and they're like, "Yes, I'll give you a tablet." So yes, online does help for me to know I go in, I say, "I've got this" and they'll agree with me and then they'll sort me out (P31, female, conjunctivitis, tonsillitis)*

*He was quite happy actually. He was just like, "Oh well that's great then. This is the page on YouTube you should have a look at. We can do it here if you want or you could just go home and do it online." I was like, "Alright then." So I just left (P33, female, anaemia)*

Unfortunately, for some participants the disclosure of their internet searching was not so well received.

*I think at the start they were quite reluctant to give me antibiotics because I went in and I was like, "I've got cystitis." I knew I had it. I was in so much pain. I'd been up crying all night. Then they were asking me questions about it, because when you ring up to make the appointment the receptionist asks you questions like stinging. I was like, "I know what I've got." So I just wanted to go in and get the antibiotics. It made the doctors reluctant to give me them because I knew quite a lot about it, because I'd researched. I'd say, "I've tried this, this and this that I've found on the internet. That's all there is left." (P30, female, cystitis)*

*Because I have sleep problems as well, erm, and they don't- they don't- they can't give you long term sleep medication. They're really reluctant to give you short term. I was like, "Well, if you give me this..." I looked at what I wanted. It was like, "If you give me this antidepressant that has got sedative effect, I'll take it before bed." He was like, "Yeah, we're just gonna see how the Prozac goes." And I'm like, "I know how it goes." (P21, male, stomach pain, when talking about a sleep issue)*

Participant 20 (below) described an occasion of conflict between herself and the HCP, who had assumed the patient had decided upon a course of action/treatment based on their health information searching prior to the appointment.

*I went to the doctor about something more recently, and I was a bit annoyed because she says "Alright, so you've already made up your mind", and she actually said "How do you, how do you want to treat it?" And I hadn't googled anything to do with treatment, and I was just like "Well, that's not my job, that's your job". I'm just coming in armed with my knowledge that, you know, these are what my symptoms are, because there's no- I don't see any reason in going in with, sort of, preconceived ideas about how it's going to be treated, unless, you know, they say "This is what we do in every case". Because with the erm health issue we're talking about mainly, I was actually quite surprised about the treatment she suggested (P20, female, breast discomfort)*

Through the interviews it was clear that a key point of conflict may be the source of information itself, its reliability, validity, credibility and trustworthiness. Participant 22 described a change in her GP's initial reaction to her online sourcing once she stated the information was sourced from the NHS website.

*Yes and her face dropped... Once I said, "No it is the NHS website. Don't worry", she said, "Oh brilliant", and then I kind of led. It was quite nice because I could lead the appointment as opposed to her just asking me a million questions (P22, female, migraine, rash)*

Patient's concerns regarding the HCP reaction to their efforts to integrate information, are taken into consideration when deciding whether or not to divulge their internet searching, with many describing feeling embarrassed to do so. P29, P25, and P24, report feelings of embarrassed often prevent disclosure their online searching.

*No I did not say that. I think that is the worst thing. I get to embarrassed to admit it, so I never admit that it could be this; I just list symptoms that I have and hope that they push me the right way... I wanted her to do a sugar level test, something else test, but she didn't, but I don't want to be like I have looked online and I have this, because they will be like I'm a doctor and I know what I'm talking about, don't look online. I can't be bothered for that lecture or embarrassment so I just don't say anything (P29, female, meningitis, anaemia)*

*Cause I think you can go a bit too far into looking into the internet a lot of the stuff I read I don't really trust it so I wouldn't want to say I've found this online and them to say that's a load of rubbish (P25, female, verruca, contraceptive pill)*

*Depending on the thing, how embarrassing it is to admit or not but, yes, I did admit this time that I'd looked it up because I did have my worries about it (P34, female, sleep paralysis, vaccinations, headaches)*

Some participants believed HCPs have a tainted view of online health information, with some participants reporting that they have been told not to use the internet as a tool for making health decisions.

*But to counter argue that, I think maybe sometimes the doctors concerned could be, if people are going to narrow things down, they have made, sort of, sort of a decision about what their medical problem is, before they see you, who might say "No, no no, based on the symptoms, blah, blah blah, it's actually..." And then they could end up with a bigger battle on their hands (P20, female, breast discomfort)*

*Irritated. They always say you should only look on the NHS website or I think they said patient.com last time, but they said you shouldn't look online (P30, female, cystitis)*

*Yes. I've said to some doctors before and they were like, "You shouldn't look up too much online because it does scare you." I still think it's good (P35, female, flu symptoms)*

Participants anticipated that HCPs may feel affronted if they decided to integrate the internet information into their decision making in replacement of, or even in conjunction with the HCPs advice and knowledge informed by years of medical training and studying, as highlighted in discussions with P30 and P23:

*Some of the stuff like the cranberry tablets I'd found that online. So I'd gone to the pharmacy and got them. So I knew that they did work because I asked the pharmacist about them, but I think the doctors get a bit annoyed that you can find out the stuff online rather than through them (P30, female, cystitis)*

*It must be difficult for them cause they go to university for seven years and then they have someone come in who has looked at one thing on the internet and they think well I know - I think there has to be a cut-off point where you are just giving them hints to what might be wrong with you by your symptoms and things and how you generally feel and then dictating to them (P23, female, rash)*

Given the apprehension of some participants to divulge their internet searching and findings to the HCP, and the potential for conflict, it would be of interest to investigate HCPs' perspectives on patients using online health information in support of their health decision making. This would provide a different stakeholder perspective and allow any tensions between the patients and professional perspectives to be exposed

#### **4.4 Discussion**

The present study aimed to investigate how individuals with short term health complaints used online health information to inform health decisions. Three main themes were reported in this chapter that show how people facing a short term health issues make use of the internet based health information to support their health decision making. Firstly, participants described using the internet primarily as a triage device, whereby information sourcing was focussed on the use of static (e.g. NHS choices) websites in order decide whether or not seek further medical advice. Secondly, online health information was used

as a stand-alone resource, where participants would purchase products, try home remedies, and make changes to prescribed medication without consulting an HCP. Lastly, the process of integrating and negotiating online health information was described, with participants evidencing both successful and unsuccessful experiences integrating online health information into consultations and discussion with HCPs.

Together, these findings showcase the internet to support decision making; prior to seeking medical intervention, during interactions with HCPs, and even independent of medical involvement. This depicts a distributed view of decision making (Rapley, 2008) emphasising that not all health related decisions are confined to medical consultations as a result of one off dyadic encounters with health professionals. This research is thus also novel in its efforts to address and investigate the range of health related decision making that is not confined to treatment choice.

Individuals with long term health conditions are likely to have consulted with an HCP on multiple occasions throughout their illness trajectory, sometimes more often as symptoms wax and wane. As discussed in Chapter 3, these patients become more expert in their condition, many of whom will have explored all avenues of available treatments and focus their internet use on improving (and keeping up to date with) expanding knowledge and alternative and natural remedies. Those with long term health concerns are likely to spend time engaging with peer-resources on sites such as Facebook groups and forums or discussion boards as they are not limited by geographical restrictions (Braithwaite, Waldron, & Finn, 1999) and can be used to gain alternative ideas, to assist with coping strategies, and for social and emotional support. Comparatively, findings in the present study reveal individuals with short term health conditions prefer static websites such as the NHS choices and Web MD that provide factual information, to assist with faster decision making predominantly concerning treatment options. This includes (as described in the findings above) avoiding interacting with HCPs altogether (for both well intentioned and less positive reasons) and choosing to go solo by making decisions based on online information without consulting an HCP. In this study, it is understood that people choosing the latter route did not wish to burden HCPs or the NHS, and may have felt empowered with a sense of responsibility to do something about their healthcare, having gathered the information independently online.

Similar to findings reported in Chapter 3, the present study also identified the influential role of empowerment in aiding health decisions. It could be argued that participants fostered feelings of empowerment as a result of engaging with online information, to fulfil

either three of the decision pathways reported in this chapter. However, in comparison to Chapter 3, participants in the present study were more subtle in their efforts to integrate and negotiate health information into consultations with HCPs. Whereas participants with long term health issues were more open in disclosing their searching to their HCP, participants with short term issues seemed to integrate the information more implicitly. This could be in part explained by those with long term conditions having more opportunities to forge a good rapport and relationship with the HCP across their illness trajectory (though we cannot guarantee participants in this study saw the same HCP each visit) and felt more comfortable to disclose the internet sourced information. However, participants in the current study were empowered to ask questions and introduce information they had gathered, and as discussions focused on obtaining a treatment, perhaps participants were less inclined to be involved in what they perceived to be a short term health issue that required little cognitive effort.

Noteworthy to mention here is how the findings highlight the proximity between using the internet as an initial information resource and formally making a decision. Individuals in Chapter 3 with long term conditions seemed to experience a more established relationship with internet use. In the initial stages of their internet searching, the sourced information planted seeds and ideas initiating the process of contemplating these choices over time, with the final decision often being made at another time or place. Comparatively, individuals with short term health concerns were outwardly more concerned with obtaining a diagnosis and sourcing a treatment as quickly as possible, thus the proximity between initial use of the internet and decisions were much closer than it was for those with long term complaints.

Internet use for health information sourcing has increased in recent years, however information can sometimes be disorganised, of poor quality and of difficult readability (Robins, Barr, Idelson, Lambert, & Zerkowitz, 2016; Storino et al., 2016) which can distress some users. In the findings reported across Chapters 3 and 4 some participants felt that online information had scared them into scheduling an HCP appointment, as well as misdiagnosing themselves with a serious health condition (e.g. Participant 32) which subsequently led them to seek medical advice. When discussing the limitations of online health searching, participants provided the same example - in that searching symptoms nearly always returned a cancer warning. Given the sheer abundance of individuals using the internet as a diagnostic tool (and in some cases using it to avoid seeing a HCP entirely), it is unsurprising that many users are becoming misinformed and resultantly

misdiagnosing themselves. These findings ring true of the longstanding concept of cyberchondria, broadly defined in te Poel, Baumgartner, Hartmann, and Tanis (2016) as online health-related information seeking that is fuelled by one's own health anxiety and that also amplifies this particular anxiety. Although this interpretation refers to a clinical level of anxiety, the downfalls of online health information such as technical language or poor quality may lead to health anxious beliefs surfacing in individuals who were not clinically health anxious before (Aiken & Kirwan, 2013; Starcevic & Berle, 2015), therefore it is conceivable that some participants in this study experienced cyberchondria, or rather that online health information triggered it at least to some degree.

*How do individuals with short term health complaints and long term health conditions use online health information to support their health decision making?*

Throughout Chapters 3 and 4, participants' concerns about information reliability and validity were prominent. Participants ensured that they consulted websites they deemed appropriate (with domains of '.co.uk' or '.org'), and in order to confirm information integrity, participants regularly engaged in data triangulation and saturation, consulting multiple information sources both online and offline before considering it in their health choices. Both samples described efforts to integrate the information into appointments with HCPs, and equally reported successes and failures in doing so. Participants in both studies considered the role of the HCP, and shared the perception that HCPs hold negative views regarding internet informed patients.

Participants indicated distinct information source preferences. Most participants in the current study emphasised their preferences for factual information sources when searching the internet for health information to assist with their health decisions. Some participants viewed information platforms such as forums and discussion groups, containing PEx and anecdotal advice, to be more appropriate for individuals with long term health issues, who are in greater need of emotional and social support. For those with short term issues, they were often drawn to statistical and factual information sourced from static information sources such as the NHS website, which assisted in quicker decision making surrounding diagnosis and treatment. As such, participants did not consider PEx information as essential to their health decision making, although some considered this useful occasionally. On the other hand, discussions with participants in Chapter 3 centred on the usefulness of OSGs and networks to support their health. These findings highlight that individuals with short term and long term health issues use online health information differently to support health decisions.

Participants also described differing motivations to use online health information to inform different types of health decisions. Individuals with long term health conditions in Chapter 3 primarily discussed consulting online health information in order to assist with condition management. For example, product decisions (e.g. purchasing a stool to alleviate fatigue and pain), and deciding to request a care evaluation from a HCP in response to new guidelines. On the other hand, participants in the present study were motivated to obtain a diagnosis and treatment, and mostly described using the internet as a triage device, helping with decisions to seek HCP involvement.

Overall, findings from Chapters 3 and 4 highlight a number of similarities and differences regarding the ways in which patients with short term and long term health complaints, use online health information in health decision making. The findings provide evidence in support of distributed decision making around health (Rapley, 2008), in which the range of 'health' decisions are by no means limited to treatment decisions within a consulting room.

#### **4.4.1 Conclusion**

The findings of this study represent a relatively understudied participant sample within the field of internet informed patients and health decision making. The findings are complimentary to those described in the previous chapter. Considering the findings from a holistic perspective, there is clear evidence in support of the view of DDM, with participants describing interactions with multiple technologies and individuals, which Rapley (2008) describes to help shape and transform decisions over time. Furthermore, participants discussed a number of health related decisions that were not limited to treatment choices within the confines of an appointment or a purely medical context, as reported thoroughly throughout published literature. Participants also recognised a number of decision making activities which they became active and involved in, from initially recognising there were decisions to be made, appraising and selecting options, to evaluating the decisions they had made (France et al., 2011). These findings add to our knowledge about the internet as a health information resource, and highlight its use across a number of different health decisions.

Upon reflection with the previous chapter findings, the present study results highlight important differences between the use of online health information to assist in health decisions, between individuals with long term and short term health complaints. Furthermore, the findings show that motivations to utilise this resource differ between

those with long term and short term health complaints. No study to knowledge has considered both perspectives, and the discrepant findings highlight the need for further enquiry. The next Chapter, seeks to identify whether health professionals views are compatible with those reported by patients in Chapters 3 and 4.

#### **4.4.2 Strengths and limitations**

Literature thus far has seldom considered how individuals with short term health complaints use online health information to inform health decisions. The findings present new data for this understudied sample. The present study is also important as it acknowledges the ability for the internet to inform a range of health decisions, assuming the perspective of DDM (Rapley, 2008). Prior studies are typically constrained to individuals with chronic health conditions, making specific treatment choices (as described in section 3.1), thus the present study provides preliminary evidence to suggest differential use of the internet for health decision making between short term and long term health complaints. Twenty two participants may be considered a small sample, however a broad range of individuals took part, representing the use of the internet to inform a vast range of health decisions.

#### **4.5 Chapter summary**

This chapter described a qualitative study designed to explore how individuals with short term health conditions use online sourced health information in their health decisions. The focus on individuals with short term health complaints was important as the literature base largely represents how individuals with long term health conditions use internet information to assist with treatment decisions. The main findings regarding consulted sources, motivations for searching, and how information is integrated into appointments juxtapose those presented in Chapter 3. However, a commonality in both studies is that patients believe that HCPs hold negative perceptions of internet informed patients. To further examine findings reported here, the next chapter (Chapter 5) describes a qualitative study undertaken with HCPs in order to investigate their views of internet informed patients.

## **Chapter 5: Healthcare Professionals perspectives on internet informed patients and decision making (Study 3)**

In Chapters 3 and 4, many participants indicated that although they were using internet resources to inform health decisions they were reluctant to discuss this with their HCP. Patients feared a negative reaction from HCPs, but there is little recent literature examining HCPs attitudes towards the use of the internet by their patients. This chapter therefore describes the findings of a qualitative study that used a number of specifically developed scenarios as prompts to investigate HCPs experiences of and perspectives on internet informed patients, how this influences the consultation, the professional-patient relationship and importantly the impact on decision making.

### **5.1 Introduction**

Recent years have witnessed increased consumer use of the internet for health information seeking. Users are thus becoming better informed and engaged in their healthcare, fulfilling UK governmental policies that advocate patient involvement and responsibility (The Department of Health, 2012). The internet has been heralded as a transformational tool within healthcare, as patients use it to prepare for healthcare appointments (Caiata-Zufferey et al., 2010) and to support decision making processes and final decisions (Lagan et al., 2010).

Patient engagement in e-health information has not negated nor displaced the role of health professionals in health information seeking; rather, emergent technologies seem to have altered the professional-patient relationship and the decision making process (Xiang & Stanley, 2017). Increased levels of patient involvement epitomises a shift from the traditional paternalistic healthcare model where patients assumed a more passive and compliant role, to one of collaborative decision making (Townsend et al., 2015). As such, online information seeking often leads to more contact with health professionals (Lee, 2008), in which patients seek to corroborate the internet findings through discussion with the GP (Sivakumar & Mares, 2016). Thus, these seemingly separate methods of information seeking are not always discrete but can be intertwined and integrated for good effect.

Today, it is commonplace to see patients arriving at medical consultations informed by their internet research; however, not all patients who have searched online divulge this fact to the HCP. This behaviour has received considerable attention within the literature with rates at which patients inform a health professional of their internet searching

varying between a third (Hay, Strathmann, et al., 2008), almost two fifths (Fox & Rainie, 2002) and almost a half of participants (Delić, Polašek, & Kern, 2006). Likewise, participants in Chapters 3 and 4 also reported their reluctance to divulge and discuss their online information searching to their HCP.

The participants discussed a number of barriers to discussing internet-based information with their HCPs. These barriers mirror those previously identified in the literature and include; fear of the professional's reaction, fear of embarrassment, simply not knowing how to introduce the information, and avoiding being viewed as troublesome or being seen to challenge the HCP's role (Joseph-Williams et al., 2014; Silver, 2015; Tan & Goonawardene, 2017). Underlying all these barriers is the potential threat to the therapeutic relationship, an understandable concern given the importance this interaction has on health outcomes (Macdonald et al., 2018; Street, Makoul, Arora, & Epstein, 2009), patient satisfaction (Bylund et al., 2007) and decision making. Interestingly, the barriers to discussing internet-based information reported by HCPs are distinct from those reported by patients. HCPs describe time pressures, and characteristics of the patient and clinical situation that do not always make discussing the patients' health information searching appropriate (Légaré, Ratté, Gravel, & Graham, 2008). The latter suggests that HCPs may screen participants on an individual basis to judge the applicability, and appropriateness to engage in conversations regarding the patient's knowledge based on internet research.

Studies, many conducted more than ten years ago, suggested that physicians' perceptions of internet informed patients were typically negative. Patients were considered misinformed, confused and problematic, and HCPs proclaimed themselves unprepared to deal with this new development (Ahmad et al., 2006). These views were upheld by a later study, where Swedish GPs described employing coping strategies to "neutralise" and "repair" internet informed patients (Caiata-Zufferey & Schulz, 2012). More recently, a small number of studies have begun to document a change in HCP perceptions leading to internet informed patients being viewed more favourably (Macdonald et al., 2018). Researchers have also noted the positive benefits to the doctor-patient relationship and the consultation that internet informed patients can bring (Caiata-Zufferey et al., 2010; Townsend et al., 2015; Van Riel et al., 2017; van Uden-Kraan, Drossaert, Taal, Smit, et al., 2010). In comparison to the abundance of literature addressing patient perspectives, there has been considerably less effort to understand the HCP perspective (Roper & Jorm, 2017), furthermore, no research has directly addressed the use of internet information in

relation to decision making discussions with patients. Authors of recent investigations explicitly call for more studies to investigate “the different ways patients and doctors perceive medical encounters” and emphasises the need for more research to seek and address doctors stories of such interactions (Arieli & Tamir, 2018).

## **Rationale**

In summary, Chapters 3 and 4 indicated that patients were concerned about disclosing and discussing online health information in consultations with their HCP. Participant reported barriers such as fear of embarrassment and fear of the HCP’s reaction support those amongst published literature. Therefore, the present study sought to better understand the HCPs views of the internet informed patient and how this affects patients’ health decisions and the patient-professional relationship. Whereas the limited research in this area has predominantly focussed on GPs (Légaré et al., 2008), the present study takes an inter-professional approach in order to incorporate the views of HCPs working in different healthcare roles and at different levels. In summary, the current study aimed to investigate HCP experiences and views regarding the use of online information in patient decision making.

## **5.2 Method**

### **5.2.1 Analysis approach**

This study employed a mixed approach to data analysis. Given that the scenarios employed in this study were developed to explore specific topics such as different information sources and integration behaviours of internet informed patients, the data analysis thus comprised a top-down element of analysis. However, emergent themes were also followed up throughout interviews, thus the analysis also consisted an element of bottom up analysis.

### **5.2.2 Participants and recruitment**

A purposeful sampling method was used to recruit 10 healthcare professionals from the North East of England. Participants were drawn from a range of health professions, and all have experience working within the NHS. This ensured a sample of health professionals working at different levels and in different healthcare roles. See Table 5.1 for each participants’ professional expertise. Participants were required to have experience of patients attending consultations with or informed by online health information.

**Table 5.1.** Participants current job role and experience as a HCP.

<b>Gender</b>	<b>Age</b>	<b>Confidence using the internet (1= not at all to 4= very confident)</b>	<b>Current Occupation</b>	<b>Experience as a HCP</b>
M	24	4	Newly Qualified – MBBS Newcastle University 2017	<ul style="list-style-type: none"> <li>• Five years medical school</li> <li>• Two years clinical experience</li> <li>• One year GP placement</li> </ul>
F	52	3	Teenage pregnancy sexual health advisor	<ul style="list-style-type: none"> <li>• Retrained from previous occupation as a speech and language therapist</li> <li>• Thirteen years’ experience in current occupation</li> </ul>
F	35	4	Doctor / GP	<ul style="list-style-type: none"> <li>• Medical degree</li> <li>• Three years in current occupation</li> </ul>
F	50	3	PhD Researcher – formerly Dentist	<ul style="list-style-type: none"> <li>• Ten years’ experience in her previous occupation as a Dentist</li> </ul>
M	49	4	Dental Surgeon and associate clinical lecturer	<ul style="list-style-type: none"> <li>• Twenty seven years’ experience as a dental surgeon and associate clinical lecturer</li> </ul>
F	44	3.5	Research/ Clinical Physio	<ul style="list-style-type: none"> <li>• Three years in current role as working in a fatigue clinic as a Researcher and Clinical Physiotherapist</li> </ul>
M	54	4	Professor in Psychology	<ul style="list-style-type: none"> <li>• Health Psychologist Practitioner</li> <li>• 3 weeks in current role as a Professor in Psychology</li> <li>• Currently works in a trans-diagnostic fatigue clinic</li> </ul>

Table 5.1. continued

M	31	4	Military GP Registrar	<ul style="list-style-type: none"> <li>• Seven and a half years experiences as a military doctor</li> <li>• Two and a half years' experience in current occupation</li> </ul>
F	44	4	Post-doctoral Researcher & Clinician OT	<ul style="list-style-type: none"> <li>• Twenty two years experiences as an Occupational Therapist</li> <li>• One year experience in current role</li> </ul>
M	26	4	Medical Doctor	<ul style="list-style-type: none"> <li>• Qualified GP</li> <li>• Experience in A&amp;E</li> <li>• Eight months experience in primary care</li> </ul>

Participants were recruited via word of mouth and social media advertisements (see appendix 9.9). Permission was granted from the local NHS Research and Development manager to circulate the study recruitment notice to local NHS staff via the weekly general communications email (see appendix 9.10).

Ten HCPs (5 Males, 5 females) aged 24-54 ( $M = 40.90$ ,  $SD = 11.07$ ) from the UK individually participated in a scenario based qualitative interview. It was important to recruit HCPs from a range of healthcare roles as differing time restrictions imposed across healthcare settings e.g. general practice in comparison to specialist healthcare clinics, might mean that professionals hold different attitudes toward internet informed patients. Participants took part in their own time and did not receive any payment or compensation.

### 5.2.3 Materials

All interviews were digitally recorded using an Olympus Dictaphone for transcription purposes. Participants provided demographic information such as age, gender, ethnicity, current employment role and medical training.

## Scenarios

The purpose of this study was to elicit reflections and insights from HCPs regarding their perspectives on the role of internet health information in patients' health decisions, using scenarios describing real patient experiences. Employing this methodology encouraged the HCPs to think aloud as they responded to each scenario, and enabled the HCPs to respond to scenarios by drawing on their own experiences where appropriate to support their discussions. This vignette method has been used frequently within healthcare settings to examine HCPs decision making (e.g. Evans et al., 2015), and was employed to good effect in a recent study of British GPs' perspectives of patients' use of self-monitoring data in consultations (West, Giordano, Van Kleek, & Shadbolt, 2016).

Participants in the present study responded to five scenarios that described occasions where patients have used online health information to assist them in making a health decision. Each of the scenarios (see examples below) was adapted from participants' experiences described in Chapters 3 and 4 and was anonymised and modified to make sense in relation to each of the health professional's occupation (see appendix 9.11 for all scenarios). The five scenarios were developed to capture the use of different information sources, how patients chose to present the findings of their internet searching to the HCP, and how patients acted upon the information. The use of scenarios in this study thus aimed to strike a balance between acting as a prompt whilst capturing detailed participant responses.

Example scenario provided to GP's:

*“Debbie was diagnosed with Diabetes 3 years ago. She has recently started to search online for information about her diabetes to help her understand and manage the condition better. She looked on the NHS Choices site and saw some useful information on there about diet but felt that she needed additional help. She printed the page from NHS choices and made an appointment to see you. At the appointment, she says she feels more knowledgeable about the condition now and has a few, well thought through questions to ask you. In addition, she asks if she can receive further help from a dietician”*

Example scenario provided for Dentists:

*Debbie is worried that she might have gum disease. She has recently started to search online for information, including the NHS Choices website, and she has checked her symptoms across a number of other websites that are also reputable. She has tried some mouth washes that she thinks might help, that she has read about online, but she hasn't seen any difference in the*

*symptoms. She has printed off some information from the NHS Choices website and makes an appointment to see you for more help. At the appointment, she feels more knowledgeable about the condition and has a few well thought out questions to ask you*

Participants were informed that the scenarios sought to elicit their perspectives on patients' use of internet resources and its role in the patients' decision making, and the influence on the HCP-patient relationship, rather than how they would proceed to deal with the medical scenario. Following each scenario, a topic guide was used to focus discussions around these broad questions of interest, however emergent issues were also pursued as appropriate.

#### **5.2.4 Procedure**

This study received ethical approval from Northumbria University's Faculty of Health and Life Sciences postgraduate ethics committee prior to the interviews taking place.

Interviews took place over an eight-month period between July 2017 and February 2018. Seven face-to-face interviews were conducted at Northumbria University, and 3 were conducted via telephone. Prior to the interview, participants completed consent documentation and were informed of the confidentiality procedures, how their data was to be used, and that they were free to withdraw from the study at any time without explanation. Once participants provided demographic information the interview and audio recording commenced. Interviews lasted between 31 and 66 minutes and participants were then debriefed and thanked for their participation.

To assure anonymity participant names were replaced with an identifying number, and in the transcription phase, all identifying data were removed.

#### **5.2.5 Procedure for analysis**

Transcribed interviews were thematically analysed following Braun and Clarke's (2006) proposed phases, as described in Chapter 3 (section 3.2.5). The researcher constructed notes following each interview and throughout the repeated reading of transcripts (see appendix 9.12 for an example). The coding process in the present study considered content of the scenarios used to structure participant interviews, whilst also coding for interesting and emerging ideas that were explored within the interviews.

### **5.3 Results**

HCPs held overwhelmingly positive attitudes to the scenarios that described internet informed patients integrating information into appointments. Thematic analysis of the

data identified two prominent themes: “*Being transparent and honest*” and “*Improving integration*”. These themes describe HCP’s encouragement for patients to be honest about their internet searching, transparent about the information source, and to integrate the information into consultations. Participants also recognised patients’ apprehensions regarding information integration and discussed the impact on the patient-professional relationship.

### **Overview**

Throughout the interviews HCP’s consistently framed their discussions of internet informed patients in a positive light, describing them as ‘proactive’, ‘engaged’ and ‘interested in their healthcare’ e.g. “*if they’re willing to help themselves and to take control of their healthcare, and their own health then I think it’s a positive thing*” (P10, male, GP). The HCPs welcomed and encouraged patients consulting online health information sources, as discussions centred on how empowered and engaged patients are better equipped to participate in their own healthcare, with e-health information facilitating aspects of the consultation such as the conversation and collaboration between the HCP and patient.

In particular, health professionals reflected upon patient’s use of the internet to prepare for appointments in a positive light. It was suggested that this enables patients to “*look into things at home in their own time and digest information at their own speed and develop any questions that they might have*” which ultimately “*helps patients to clarify in their mind what decision needs to be made*” (P3, female, GP).

Professionals also demonstrated encouragement in favour of patients integrating online health information into appointments. For example, letting the patient have their say “*means you know what you’re doing with the session, and it’s a good basis to start off a conversation*” (P7, male, Professor in Psychology), but also they can “*work through whatever they say and build it into your explanation or your reasoning or your decision*” (P8, male, GP). This implies that HCPs are constantly working to incorporate the patient’s perspective and knowledge into their own initial ideas, in order to assist with mutual, shared decisions.

The overarching positive views voiced by HCPs in this study can be summarised by Participant 1 who stated, “*It does take a bit more time to talk through shared decision making... but if it has better outcomes, and better patient compliance, and better patient*

*satisfaction, then it's definitely something we should be doing, to encourage people" (P1, male, GP).*

The overwhelming positive outlook by HCPs persisted as they more specifically discussed the importance of patient honesty regarding their internet searching and being transparent about the sources they have consulted.

### **5.3.1 Being transparent and honest**

This theme is defined by the way that participants (HCPs) emphasised the importance for patients to be honest by informing them of their internet research, as well as being transparent regarding the information source. According to the HCPs, if patients are honest and transparent about their internet research, it enables them to understand the patient's worries and concerns and presents the opportunity to signpost to other appropriate information sources and ensure that patient's decision making is not affected by biased information.

*It's always the core technique we were taught to deal with it, is to find out what patients already knew, which they might offer themselves willingly, if they have looked up something on the internet for example. Or actually, sometimes you might need to ask, to ascertain what they've already found out... that if patients have looked up anything on the internet, or got it from a source such as a relative, that you actually elicit it quite early on, to try and deal with that... Because if you don't elicit it, they might not offer it, and then hence, nothing gets done and it just rots on. The patient will just not have changed any attitudes from before they came in, because they haven't been communicated with in a way that elicits that, and can make changes to their views on it (P1, male, GP)*

*We need to understand what she understands. I need to, first, seek to understand her – and her perspective on things (P6, female, Clinical Physiotherapist)*

*...because if they've got a niggling doubt or fear or worry, if you don't get that out into the centre of the session, you're going to be on a highway to nothing (P7, male, Professor in Psychology),*

Participants recognised that patients may feel apprehensive about divulging their internet searching but wanted to reassure patients that they welcome and encourage open discussions and described the benefits to the consultation. For example, it enables the HCPs to tailor and plan the remainder of the session or appointment accordingly and

ensures that they are making the right decisions for the patient. Participant 4 sees this honesty as a good way to introduce the conversation.

*I think they feel that the health professional is going to disapprove of that, or maybe feel threatened by that... Maybe patients think that the health professional is going to feel that the patient is trying to be too pushy. As a clinician, I don't believe that at all. I'm quite happy if patients have got their own information, I would just rather they're honest and then I can help them out. I don't have a problem with it at all... If they do open up, sometimes the fact that they've looked online can help with the conversation. You can say, "Oh, tell me what you've found out." It can actually break the ice a little bit (P4, female, Dentist)*

*It's easier to drive a consultation when you know what the patient is worried about. The worst-case scenario is that a patient is worried about something really massive and they don't tell you, and you tell them what you think and it doesn't match up with what they think, and they go away unhappy and still worried. So it's actually a positive thing to know what's going on in someone's mind, because it might be that there's one very simple explanation you can give as to why that's not the case; you could virtually rule it out in that consultation and make the patient feel a lot better (P3, female, GP)*

*I think as long as patients are honest about it. Because again, that sort of drives the consultation a certain way. Yes, just that patients be honest about it, because as doctors, especially for myself in particular, the reason I'm asking my questions and the reason I'm doing the things I'm doing, is to help the patient. I don't believe in just telling people what to do and they should do it, because I know more, I've got a medical degree, and all that...But if there's something that the patient is holding back, then I can't be certain that I am making the right decisions for that patient (P10, male, GP)*

An extension of this benefit was that the HCPs were able to determine whether the patients had any preconceived ideas regarding the content and outcome of the appointment. Many of the HCPs described having to manage patient expectations, particularly if they have read something worrying or something that did not align with the HCPs diagnosis. They then had to work this into their communication with the patient.

*It might be that they've come in and they've Googled 'headache' and they've decided they've got a brain tumour. Now, let's be honest, 1 in 3,000 will. The rest won't. It's my job to reassure them as to why the headache they've Googled isn't*

*the headache that's caused by a brain tumour. It's really, really useful to find out why they've looked at what they've looked at because they may just need a bit of reassurance. Or they may be expecting a brain scan and actually you can go, "Look, you've had this headache every month for the last 20 years. If it's a migraine it doesn't need to have a scan," but explain why. Don't just go, "No, I'm not giving it to you," if you know what I mean (P8, male, GP)*

*Even if they use it, and they come in and they are expecting really ambitious stuff – and I have to say, "I'm sorry, I can't do it." That's fine, because at least we've addressed it. The internet is around - it's out there - so I'm okay with people using it, but I'd quite like to know how they've used it (P4, female, Dentist)*

Together with encouraging the introduction of internet informed information into the appointment, HPCs also emphasised the importance of knowing the information source. Participant 2 emphasises the need for HCPs to engage in source appraisal, in order to consider whether the information is balanced, credible, appropriate and accurate before incorporating the information into decision making.

*I'd like to know the source. I don't expect other patients to be going trawling through MEDLINE and all of the sort of like academic databases, but if it's something like a Facebook post that someone has posted somewhere, that's gone viral, or whether it's a legitimate source, essentially, I think is the main thing for me. Whether it's actually applicable to that patient as well (P10, male, GP)*

*I think definitely the information source, that would give me a good feel as to whether they're getting accurate information or not. At the same time, I think it's always useful to connect with others that have got similar experiences. I think some negatives I've come across, actually, it would be more people suggesting quite whacky ideas online (P9, female, Occupational Therapist Clinician)*

*So it's, where do you find positive advice? Well, there's advice around it, but it's positive feedback, or anything positive that's written. Because a lot of it is very, very negative. Then, depending on where you look, as well, they will really, really paint a bad picture of abortion. So that's definitely somewhere where we have that conflict, and where it has an impact on that person's decision (P2, female, Sexual Health Advisor)*

This awareness surrounding the balanced nature of the information was recurrent throughout interviews, as professionals also describe their concerns surrounding information authorship.

*The thing about the World Wide Web is it's worldwide. If you go onto a website from Thailand, Japan or something like that you might have a very different emphasis in treatment to we would necessarily think about in this country. I would always ask, "Was it a website based in this country? Was it NHS Choices? Was it Boots MD? Was it one that was sponsored by one of the universities or something like that where there's proper peer-reviewed sensible information?"*  
(P5, male, Dental Surgeon)

*There are lots of people out there - with chronic conditions - saying, "I can solve your problems." For some people it works, and for some people it doesn't. It tends to be quite expensive, and it's not evidence-based or well-researched* (P6, female, Clinical Physiotherapist)

An outcome of this source appraisal was participants' signposting patients to appropriate information resources, in order to ensure that the patients' future decisions were informed by appropriate, reliable, credible information.

*Because if she's open and says which websites she's looking at, we can be like, "Well, actually, that's not the best one to look at," or, "That one is really good. The information on there is really good," so that, hopefully, that might become her first port of call, say, the next time or whatever* (P2, female, Sexual Health Advisor)

*If the patients' feel like they need more information, then I feel like, if you can say, "Well, good for looking at this, but actually, there are other resources out there," and maybe signposting patients towards it... leaflets and handwritten information that's been approved by NHS sources, and usually charitable bodies and stuff, so people could go there. And you could direct them to other sites that are more trusted. So some forum websites, we don't trust as much, because the people who write them aren't medical professionals, it's just other patients with similar conditions. But actually, there are some websites, like the Arthritis Research UK and stuff, who are professional bodies, but do have a forum site. And so not just dismissing which ones are horrendous, and bad sources of information, but just guiding them to more reliable and trustworthy sources* (P1, male, GP)

The above quote carries substantial importance, as the participant stresses that patients will not be dismissed, regardless of the information they bring to the consultation. This is interesting given that in previous studies (Chapters 3 and 4) a patient reported barrier to

integrating information in to the consultation was embarrassment and fear of the HCPs reaction. This gives some early indication of discordance between professional and patient perspectives.

In summary, HCPs in the present study encourage patients to be honest about their internet searching. In doing so, conversations can be initiated, and HCPs are then able to address and quash the patients worries or concerns, a process which assists greatly with the remainder of the appointment. HCPs also advocate patients to be transparent about the source of their information, as this affords the HCPs the opportunity to appraise the information and signpost to appropriate resources going forward.

### **5.3.2 Improving integration**

This second theme encompasses HCPs discussions regarding the integration of online health information into appointments. Specifically, participants acknowledged patients hesitations to integrate their information searching knowledge into the appointments, but reinforced the benefits of doing so to the appointment. Participants provided guidance on how to sensitively, and non-confrontationally introduce the information without impeding the patient-professional relationship.

As reflected in the quotes below, reported benefits of integrating the information included empowering the patient and engaging in conversation, which could potentially influence patient compliance with advice and shared decisions.

*I know time pressure doesn't always allow that, as much as we'd like, but actually, to win a patient back on board, and that might help their compliance, and then their overall control of their disease. Just to spend that time, and to encourage patients to look things up, but also to come and discuss them with their doctor (P1, male, GP)*

*they can ask you things, you can talk about things and they go, "That agrees with what I've read up about this." You're reinforcing what they've read already. That can actually be very empowering to the health professional/patient relationship. Then everybody is singing from the same hymn sheet (P5, male, Dental Surgeon)*

HCPs empathised with patients' apprehensions to disclose their internet searching and understood that they may feel reluctant to disclose their searching through fear of being perceived as a problem patient and to avoid disrupting the patient-professional balance.

*I think, sometimes, patients think that - if they disclose that they've looked online - it's going to set up a barrier and the clinician is going to go, "Oh right, so you*

*think you're an expert then?" Kind of style. I've actually never seen that happen. Maybe patients believe that it might (P4, female, Dentist)*

*I think, firstly, they feel that the health professional might shut them down. I feel, again, that sort of culture where people feel that doctors are going to tell them what to do, and tell them what's best, and take charge. Some people feel a bit apprehensive about- almost challenging the health professional that they're seeing. I think they do it perhaps to not offend them, and again it's sort of- a lot of it's behind that (P10, male, GP)*

The HCPs were also aware that patients might feel embarrassed to disclose their searching due to their lack of knowledge and potentially misinterpreting information. This reinforces discussion in the previous theme that addressed HCPs preferences for source transparency in order to signpost patients to appropriate resources. Participant 9 works in a specialised fatigue clinic working with chronically ill patients, and provides an interesting insight into patient feelings of embarrassment for this particular group.

*I think that they maybe think they're disrespecting the doctor by doing that, as in taking things into their own hands. I think that patients generally know the limits of their knowledge and they might be embarrassed to think that you might be judging them for thinking that they know more than they do... I don't know why else; probably because they know the limits of the internet and they know that they don't know the whole story, and so therefore they don't know whether they can trust it. They probably think, "Are they going to think I'm ridiculous for even suggesting it?" (P3, female, GP)*

*I think sometimes when people have gone down that route and then they've lost a lot of money or they've lost hope or it might be time, it might be money, whatever, if they've done that before they get to you, sometimes they're a bit embarrassed about that and actually a bit broken about it as well... a lot of people that come to our clinic, their symptoms have already been dismissed, so they're coming in a little bit wary. It might be that they're frightened to get a negative response from a healthcare professional, which is not a nice thing to experience (P9, female, Occupational Therapist Clinician)*

HCPs described attempting to maintain a good therapeutic relationship with patients by being accepting of internet informed patients and not dismissing the information. However, participants raised concerns regarding the potential for conflict on occasions where the professional's views conflict those of the patient that were informed by "Dr. Google".

*I suppose the issue would be if there was a disparity between what you think is wrong and what Dr Google thinks is wrong. Every day you have to justify every clinical decision you make. The difference is Dr Google's reputation doesn't stand or fail by the diagnoses that it makes. That's the difference (P5, male, Dental Surgeon)*

*They'll often come in and hope or ask, "Is this available on the NHS?" Sometimes there is a mismatch in the understanding, so patients will say, "Oh by so-and-so has got very similar teeth to me, they got theirs on the NHS, why can't I?" That's a perfectly understandable question. It's because there is a lot of confusion about who is eligible and who isn't... It's not always what the patient wants to hear, unfortunately (P4, female, Dentist)*

*when patients come armed with information and sort of their own expectations because of what they've read online, it can make the consultation quite difficult. Because once you get an idea in your head, it's quite hard to dissuade you from it (P10, male, GP)*

To diminish the opportunity for such conflicts to arise, HCPs explained how patients can introduce their internet searching to facilitate discussion with the HCP, in order to reach a shared decision. For example, Participant 8 stated *"I'd rather someone come and engage with me and say, "I'm thinking about..." rather than, "I've done..." (P8, male, GP).*

*Often you'll get a patient walk in and say, "I've come because I want you to refer me to the dietician," or, "I've come because I want a referral to an endocrinologist," or something along those lines. That is less of a positive opening statement than, "I've been Googling on the internet and I've got some questions," which is a positive thing. But when patients become demanding, it puts you on the back foot, unfortunately... because we're being clamped down on our referral rates all the time and, in certain practices, those referrals are all vetted by the team, so your colleagues have to decide whether it's appropriate as well, which puts you in an awkward position if a patient is demanding a referral and your team doesn't think it's appropriate (P3, female, GP)*

*It depends on the patient's intentions. If they are using that information to- there's no nice way to put it, to get their own way, regardless of anything, or the facts in the in clinical presentation, then I think it causes a lot of problems (P10, male, GP)*

A particular recommendation was for the patient to use internet information to inform their knowledge and to assist with the appointment, as opposed to using it as a diagnostic

tool. HCPs were concerned that patients use of the internet to inform a diagnosis could have damaging effects on the patient and the professional-patient relationship.

*I think that when the patient comes with a diagnosis to a GP clinic, rather than with a presentation or a symptom, that's quite difficult to discuss that with the patient, without being quite dismissive, and potentially disengaging them from future visits, and damaging the rapport, just because they've come in, thinking that they've got this good information, they think they've done the doctor a favour. And actually, you've got to dissuade them, and argue against that. It's okay, so I know argue is probably the wrong word, but talk them out of that situation, and that can maybe be quite hurtful to patients, that that they've thought they were doing the right thing, and then it turns out that there's that conflict with a doctor and a patient, before you even discuss their symptoms (P1, male, GP)*

*Within the clinician-patient encounter you can use information from the internet to explain and reinforce the diagnosis and the decisions that you're making. That's an unequivocally good thing. It's just an information gathering and imparting exercise. The issue comes when you try and use the internet or algorithms within the internet to derive a diagnosis. That's when potentially it can be at the very least misleading and at worst positively dangerous. Extremely worrying and cause a lot of unnecessary worry and that is really unfortunate (P5, male, Dental Surgeon)*

HCPs considered how mutual contributions from the patient and themselves can affect the integration process and the relationship. For example, HCPs described the patients' responsibility to introduce the information thoughtfully, but also how their own reactions to this behaviour is important, as negative reactions may disengage patients from future efforts to engage in their healthcare.

*I've seen a mug about surgeries which says, "Please don't confuse your Google search with my medical degree," and I think that that is a really negative thing to have on your desk because it's almost saying, "I know best; don't suggest anything because I know what I'm talking about and you don't." It's really paternalistic and I really don't like it (P3, female, GP)*

*I think if you cultivate the fact that you're open to that, then they're much more likely to bring it along... It's the old principles of counselling, of unconditional positive regard, and non-judgement. I think they are key (P7, male, Professor in Psychology),*

The fragile nature of the patient and professional relationship was further established as participants discussed how their reactions to informed patients could facilitate or prevent patient discussions. Participant 5 describes judging his reactions based on the relationship he has built up with each patient.

*I think one of the tricks with anything a patient has done to engage is- the fact they're engaging is brilliant and it's massive and it's a huge part of the consultation. What you can't do, regardless of how useless that information might be, you can't dismiss it. You've got to acknowledge they've made some effort because at the end of the day they're coming to you with some form of idea and expectation about what's going to happen from that. If you dismiss it, the whole construct that they've built up in their head about how it's going to go with the doctor is completely ruined. It can really knock off the patient/doctor interaction massively (P8, male, GP)*

*I think it depends on the patient and the health professional. You know, how well received it is and how well the... So how well the healthcare professional receives the information, and how well researched the information is. In an ideal world they'd say, "I've gone and I've looked at this, and it looks ideal." Health professional, "Oh yes, it is really... That's great." ... "I don't look at stuff like that, you should just do as I say." Then it's going to close everything down (P6, female, Clinical Physiotherapist)*

*It all depends on the relationship between the clinician and the patient, doesn't it? If you've known the person for a long time you can say, "Where did you get that from?" But you can't say that if you've just met them, can you? Even though you want to, you can't. You've then got to go through the whole, "Right okay, that is one of the possibilities. I think what we need to do is work through this and find out." The issue is one of time. You're probably going to have to spend another 10 or 15 minutes over and above your allotted 10 minutes getting the patient to a position where they can be open-minded about what their condition might be and willing to take your point of view (P5, male, Dental Surgeon)*

In summary, HCPs in the present study acknowledge that patients can feel apprehensive about discussing online health information with professionals. They suggest positive ways in which patients can integrate the information into appointments to support and improve decision making. Importantly, HCPs reinforced the significance of the therapeutic relationship and recognized the role of both patient and professional in maintaining this relationship and its beneficial effect on shared decision making.

## 5.4 Discussion

The present study aimed to investigate HCP's experiences and views regarding the use of online health information in patients' health decision making. Two main themes were identified in relation to how online health information influences patient health decisions. Firstly, HCP's held positive views on internet informed patients integrating online health information into consultations, acknowledging the benefits this has to the appointment, the patient's health, and the collaborative decision making process. According to HCPs, patients' integration of online health information into appointments opens up discussions and encourages patients to take a more responsible role in their health decisions. Patients may feel empowered through their contributions to discussions and through expression of their ideas and concerns. Ultimately, this creates a positive, respectful environment for shared decision making to take place, as the patient and professional can contribute equally without disrupting the professional-patient relationship.

This overwhelmingly positive outlook reflects a shift in thinking. Early literature in this area described HCPs "neutralising" patients in order to cope with their attempts to integrate internet information into the appointment (Caiata-Zufferey & Schulz, 2012). Despite a recent finding by Grünloh et al. (2018) that revealed a negative response by HCPs regarding the involvement of technology in healthcare, the only negative attitudes expressed in the current study were the HCP's perspectives on patients using online health information to make their own diagnoses. However, this should not detract from the generally positive nature of discussions, as HCPs simply expressed concern for the patients' health when self-diagnosing using internet criteria, rather than holding negative responses per se to patients' use of the internet to inform health decisions. These positive discussions fit with the small but recent literature that sees HCPs acknowledge that internet informed patients ask more questions and engage in dialogue, which gives professionals the opportunity to address patient concerns and expectations (Van Riel et al., 2017). On the whole, integrating information searching into the HPC appointment may play an important role in improving patient empowerment, and positively affect the consultation and professional-patient relationship (De Rosis & Barsanti, 2016).

Previously, professionals and patients identified time pressure as a barrier to the integration and discussion of internet sourced information in appointments (Légaré, Ratté, Gravel, & Graham, 2008; Ahmad et al., 2006; van Uden-Kraan et al., 2010). However, professionals in the current study demonstrated their openness for patients to integrate the information in spite of impending time pressures, and reported the benefits to the patient

and relationship outweigh the cost of running late. This perspective poses an interesting juxtaposition to findings reported in Chapters 3 and 4, where patients recalled being criticised for their efforts and attempts to introduce new ideas about their healthcare into the appointment.

A novel finding showcased in the present study was that HCPs acknowledged that the ways in which patients integrate the information into the appointment, and the ways in which the HCP reacts to this could affect the success of the integration process and subsequently the patient-professional relationship. HCPs have seldom considered the influential roles of both patient and professional in tandem when discussing the barriers and facilitators to internet information integration. This finding thus extends previous work that identifies how different communication styles of HCPs affects the patient satisfaction with their HCP (Finkelstein, Carmel, & Bachner, 2017).

Overall, the present study established a shift in HCP's perspectives regarding internet informed patients. In part, this may be attributable to the proliferation and advancement of technology that provides access to online health content, that has occurred over the past decade. More accessible health information both online and on television may trigger the population's interest in their own healthcare. Furthermore, the well-documented pressure on the NHS may encourage patients to take a more responsible role in their own, or loved one's healthcare, assuming the role of an expert patient in order to be efficient in, and optimise appointments with HCP's (Chapter 4), or to self-manage long term health conditions (Chapter 3). The blending of traditional health resources (patient decision aids/leaflets and face-to-face communication) into the online sphere could be interpreted by patients as permission to themselves to use online health information to inform knowledge and health decisions. Patients and professionals are aware of and make use of online and offline resources to inform health decisions and support healthcare, embodying the notion of DDM (Rapley, 2008). Perhaps the overwhelmingly positive perspectives reported in this study are reflected by the evolution of technology and the ways in which it is used to support healthcare.

The second main finding of this study relates to the discrepancies between patients understanding of HCPs views on internet informed patients and HCPs actual views. In Chapters 3 and 4, patients reported a number of barriers that prevented their integration of information into the appointment; however, the data from HCPs in the present study provide no evidence to substantiate these patient expectations. For example, patients in Chapters 3-4 and in the literature (Silver, 2015; Tan & Goonawardene, 2017) report

feeling embarrassed about their information searching due to the potential for misinformation, and consider this as a barrier to their information integration. These concerns about information credibility have been shared by HCPs (Ahluwalia, Murray, Stevenson, Kerr, & Burns, 2010; Ahmad et al., 2006), possibly underpinned by time restrictions imposed on healthcare appointments preventing HCPs from conducting an appraisal of the information with the patient. Contrary to previous findings, HCPs in the present study welcomed the integration of information regardless of information quality or applicability, and instead viewed this as an opportunity to initiate discussions with the patient and signpost to appropriate online health resources. HCPs in the present study seem to avoid discouraging participants from future online searching and encourage the integration of their sourced information into appointments. It is possible that the quality of health information online has progressed since some of the earlier research, and HCPs in the present study may feel more comfortable knowing that credible websites such as the NHS are well known and well used and are subsequently less likely to eschew internet informed patients on the basis that their information is likely to be reliable.

In Chapters 3 and 4, participants described occasions where their attempts to integrate online sourced health information into the appointment were dismissed. Dismissal of information, or discouragement to integrate the information by HCPs was not evident in the current study. Rather, HCPs described their preference for patients to be open and transparent about their internet searching, so that they could understand the patients' topic knowledge, concerns and expectations. This is an interesting finding given that participants in Chapters 3 and 4 described their internet searching to be motivated by their need to be on a level playing field with the HCP. This mutual awareness of knowledge differences between the HCP and patient suggests an understanding and motivation to work collaboratively throughout the appointment to come to a mutual decision.

On the other hand, patients also described occasions where their searching was encouraged. This seemed to occur when patients held a good relationship with their HCP. This poses an important consideration regarding the professional-patient relationship and care quality. Traditionally, families consulted with the same GP on each occasion, which provided substantial opportunities to develop a good patient-HCP relationship. Today, it is more common to consult with a different GP upon each visit, thus opportunities to build rapport are more difficult. The importance of the HCP-patient relationship is well documented, a sample of British GPs reported that a good prior relationship attenuated feelings of threat when patients introduced online health information into the

consultation, and GPs used this to support health promotion. A poor quality relationship however meant that the introduction of online health information into the consultation made the GP feel undervalued, leading to more stress within the doctor-patient relationship (Ahluwalia et al., 2010). This issue draws important health implications, as patients who have fostered a good relationship with their HCP are likely to obtain better health outcomes, and decision satisfaction (Street et al., 2009), than patients who do not hold such positive relationships.

In light of the above findings, future studies should examine the characteristics of internet informed patients, to investigate what sources are consulted to inform which health decisions, and how this affects integration and decision satisfaction (e.g. Chapter 6).

#### **5.4.1 Conclusion**

On the whole, HCPs in the current study voiced positive views regarding patients integrating internet sourced health information into appointments. Participants described this as assisting with patients' communication of ideas, worries, and concerns, which can subsequently positively impact the patient-professional relationship and the process of shared decision making. In contrast, participants in Chapters 3 and 4, report a number of barriers preventing the integration of information into the appointment. The discordant findings between patients understanding of HCPs views, and HCPs actual views of internet informed patients, set the scene for future work to build on bridging the gap between patient and HCPs expectations and in increasing the integration of health information into consultations (see Study 5). By increasing integration, benefits may be observed to the patient-professional relationship; so that the patient feels satisfied and empowered having engaged in a shared, collaborative decision.

The present study further emphasises the importance placed upon patient integration of information into the appointment by HCPs and patients. However, recent reports suggest that the medical community fails to support HCPs who are overwhelmed or frustrated by the internet informed patient (Roper & Jorm, 2017), furthermore that "educational interventions designed to change attitudes and give medical students or doctors the skills to better work with IIP [internet informed patients] are currently lacking" (Roper & Jorm, 2017, p65; Masters, 2016). Any negative attitudes to internet informed patients may therefore be underpinned by institutional and structural problems faced by medicine and healthcare (e.g. lack of appropriate skills and knowledge training and time restrictions), rather than their own personal and professional opinions. Nonetheless, these findings

contribute further evidence in support for additional training for HCPs on the internet informed patient and getting the most out of such appointments.

#### **5.4.2 Strengths and limitations**

HCPs provided an interesting perspective on internet informed patients. By obtaining HCPs perspectives, comparisons can be drawn between professional and patients' views and expectations on this topic, and provides an interesting vantage point from which to reflect on earlier work reported in Chapters 3 and 4. The participant sample represents a range of HCPs who differ in their roles and expertise, this is a strength of the present study, as previous research primarily consists of GPs, and is lacking in comparisons to patient perspectives.

The organic progression of Studies 1 and 2 to the present study afforded the opportunity to employ and develop a unique research methodology pertinent to this research. The focus prompt method is a superlative method of interview to understanding online information seeking (Lee et al., 2016). The use of scenarios as a focus prompt for interviews enabled the researcher to collate views from different stakeholder perspectives; in order to tease out any tensions as well agreements between patients and HCPs on the topic of internet informed patients within healthcare. However, it is pertinent to acknowledge that participants in this study reported being confident in their knowledge and use of the internet. That is, older HCPs who provided paternalistic healthcare for many years, may hold more negative views on internet informed patients, in comparison to the professionals interviewed in this study. Professionals in this study shared overwhelmingly positive views on internet informed patients, and compare favourably with emerging literature discussed in section 5.4 above. This may be attributable to the youthful sample of health professionals who took part in this study. Many of the HCPs practice healthcare in an age where technology has developed alongside their medical career and are perhaps more accepting of the implementation and integration of technology within healthcare. Additionally, it is possible that professionals who may hold negative views refrained from volunteering to participate. Thus, interpretations of the finding should consider the lack of older HCPs and negative views on the integration of internet information in healthcare.

Ten respondents is a relatively small sample, however data saturation was achieved early and persisted throughout the remaining interviews despite the varying years of practice, experience and present roles of the HCPs interviewed. The repetition of issues across all

participants suggest these findings may be transferable to other professionals in healthcare environments.

## **5.5 Chapter summary**

This chapter described a qualitative study designed to explore how healthcare professionals perceive the role of the internet in relation to patients' decisions, as well as their views on internet informed patients and the integration of information into consultations. The focus on healthcare professionals was important given that patient views had been previously addressed (Chapters 3 and 4). HCPs generally held positive views on internet informed patients, which compares favourably with current, emerging research that also considers the HCPs perspective. Findings highlight a conflict in views between the patient and the professional, and encourages future research to investigate how information integration be improved.

## **Chapter 6: Survey investigating how online sourced health information is integrated into health decisions, and influences decision satisfaction (Study 4)**

Previous literature acknowledges the use of both static (factual) and narrative (PEX) information in health decisions. The results reported in Study 1 and Study 2 (Chapters 3 and 4) highlighted a number of interesting findings. In particular, three issues warrant further investigation. Firstly, it was apparent that there were a number of different pathways through which the online health information impacted upon the way people felt about their decision making, or their overall satisfaction with their health decision making (e.g. empowering processes). Secondly, people with long term and short term health conditions appeared to access internet based health resources for different reasons, as well as search for and use different kinds of information resources. The way in which people chose to integrate their online findings with their HCP also differed. For some people, the online resources prompted goal-oriented action in the consultation room, for others an improved confidence about communicating health issues with relevant others. For some however, the resources allowed people the opportunity to bypass the HCP altogether and to make decisions alone. In this chapter, these findings are studied with a larger sample, to examine a broader range of decision types, health conditions and to explore quantitatively some of the pathways that may be important in linking online resources to decision satisfaction.

### **6.1 Introduction**

As discussed in Chapter 2 (Literature Review), patient empowerment can be fostered through the use of e-Health information such as online support sites and social networks that are known to generate social and emotional benefits (Kennedy et al., 2014; Vassilev et al., 2010). Patient empowerment is thought to facilitate condition management and compliance (Anderson & Funnell, 2010; Prigge, Dietz, Homburg, Hoyer, & Burton, 2015), contribute to reduced healthcare costs (Kuijpers, Groen, Aaronson, & van Harten, 2013) and promote collaborative approaches to healthcare. As a result, patients are better equipped to contribute to discussions with their HCP and take a more active role in consultations to engage in shared decision making (Caiata-Zufferey et al., 2010). Increased patient engagement in health care is thus associated with improved quality of life (Anderson & Funnell, 2010).

Seeking health related information online has empowering effects, for example, individuals engaging in OSGs report being better informed and increased confidence in their physician (Bartlett & Coulson, 2011; Buchanan & Coulson, 2007; Campbell, Coulson, & Buchanan, 2013; van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008). Similar findings were reported in Chapters 3-4, as participants reported that online health information helped them decide whether to seek HCP intervention, and described their efforts (successful and unsuccessful) to integrate (or not integrate) the information into the consultation. Specifically, participants in Chapter 3 reported two key empowering processes; knowledge acquirement (cognitive empowerment) and feeling supported (affective empowerment), that were obtained through their online health information searching, which helped them make a health decision. Thus, it is of interest to further examine these empowerment findings in the present study and to investigate whether empowerment leads to decision satisfaction, as literature reports a significant correlation between patient empowerment (e.g. feeling informed and making an informed choice) and decision satisfaction (Martinez, Schwartz, Freres, Frazee, & Hornik, 2009; Spence, Gilbert, Smith, & Leslie, 2010; Tambuyzer & Van Audenhove, 2015; Wong et al., 2000). Given that this thesis (Chapter 3) and previous literature (Bartlett & Coulson, 2011; Campbell et al., 2013; Mo & Coulson, 2014) identify that empowering processes are primarily obtained from PEx information in online support and discussion groups, the present study seeks to further examine whether the two key empowering effects obtained from PEx information in Study 1 (cognitive and affective empowerment) can affect decision satisfaction. In consideration of these findings, it is expected that there will be a relationship between PEx, empowerment, and decision satisfaction.

Chapter 2 (Literature Review) described how consumers of online health information employ heuristic and analytical processes to inform judgements of website trust (Briggs et al., 2002) to help determine information usefulness. For example, perceived homophily, i.e. the perceived similarity a consumer ascribes to a message source, is associated with information engagement (Sillence et al., 2014) and likelihood to act on advice (Wang et al., 2008). Participants in Chapters 3-4 also described attending to website indicators of trust, message content and message author to inform their trust evaluations, before considering the information in their health decision making. Therefore, as trust affects consideration of information for health decisions, the present study also seeks to examine the relationship between perceived trust and decision satisfaction. It is also of interest to examine whether empowerment can affect this

relationship, given that empowerment is positively associated with decision satisfaction (as described above). Therefore, it is anticipated that there will be a relationship between trust, empowerment, and decision satisfaction.

Findings reported in Chapters 3-4 dovetail with those of published literature, and show empowered patients assume responsibility for their healthcare through engaging with online health information. In some cases, patient empowerment manifested in patients integrating online health information into appointments with their HCP in order to collaborate in making a health decision. Patients' readiness to be involved in their healthcare decisions epitomises a shift from the traditional model of paternalism, to one of mutual participation and shared decision making, characterised and facilitated by a more balanced input in discussions from the patient and health professional. However, willingness to integrate online health information into appointments with health professionals can be influenced by the patients fear of the HCP's reaction (Hay, Cadigan, et al., 2008), consultation time pressures (Sommerhalder, Abraham, Zufferey, Barth, & Abel, 2009), as well as encouragement or discouragement to discuss the information by a family member (Silver, 2015) or doctor (Tan & Goonawardene, 2017). Fear of embarrassment consistently emerges as a prominent barrier preventing patients disclosing their online searching, as patients believe they lack the appropriate skills to appraise the reliability of health information and websites (Silver, 2015). Although some patients report lacking confidence to critically appraise the online health information, many report acting upon suggestions and advice obtained from patient narratives in place of seeking professional opinion (see Chapters 3-4). Also, findings in Chapter 4 highlighted that individuals with short term health complaints primarily used the internet as a triage tool, to help them decide whether to seek HCP involvement. As such, individuals with short term health complaints are perhaps more likely to integrate online health information into appointments. The present study thus seeks to examine whether individuals with short term and long term health conditions differ in their integration behaviours.

## **Rationale**

In summary, previous chapters (Chapters 3-5) highlighted a number of different pathways through which online health information impacted upon the way people felt about their decision making, or their overall satisfaction with their health decision making. Furthermore, qualitative findings also showed that people with long term and short health conditions appeared to access different types of health information to support different

decisions, and acted upon the information differently, in terms of integrating it into healthcare appointments.

In the present study, these findings described above are examined quantitatively using an online survey, with a larger participant sample. Quantitative exploration seeks to identify some of the pathways that may be important in linking online resources to decision satisfaction, such as the use of PEx information, patient empowerment and website/information trust. To knowledge, no previous study has simultaneously investigated how individuals with short term and long term health complaints use and integrate online health information into their health decisions, identifying possible mediators to influence decision satisfaction. Therefore the present study aimed to:

- (1) Explore any differences how individuals with short term and long term health conditions use the internet to support health
- (2) Examine reasons underpinning decisions to integrate, or not integrate online health information into appointments with HCPs
- (3) Use mediation analyses to explore pathways linking PEx, trust, and empowerment to decision satisfaction

## **6.2 Method**

### **Survey development: Issues measuring empowerment**

The absence of a clear definition for empowerment (as discussed in Chapter 2) means that there is no universally accepted measure, though a number of condition specific empowerment scales have been published, for example, the Empowerment Scale for mental health (Rogers, Chamberlin, & Ellison, 1997), the Diabetes Empowerment Scale (Anderson, Funnell, Fitzgerald, & Marrero, 2000), the Patient Empowerment Scale for cancer (Bulsara, Styles, Ward, & Bulsara, 2006), and the Genetic Counselling Outcome Scale for clinical genetics (McAllister, Wood, Dunn, Shiloh, & Todd, 2011). Barr et al. (2015) conducted a systematic review to assess the quality of 19 patient empowerment measures. Methodological quality of studies measuring empowerment were assessed following the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) criteria (Mokkink et al., 2010; Mokkink et al., 2009; Terwee et al., 2012), as well as criteria developed by Terwee et al. (2007) to evaluate the psychometric quality of the questionnaires. The findings of Barr et al. (2015) study informed the materials employed in this research and are described in the Procedure and materials section.

### **6.2.1 Design**

This study utilised a correlational design. This design was used in order to optimise participation and in order to capture a broad range of long term and short term health conditions, which comprised a variety of health decisions informed by online health information. The independent variables were trust and PEx. The dependent variable was participants' decision satisfaction. The mediators were empowerment subscales (e.g. cognitive empowerment and affective empowerment).

### **6.2.2 Participants and recruitment**

Participants were recruited using opportunity sampling. The survey link was advertised across social media platforms (Facebook, Twitter, LinkedIn and Reddit), email distribution lists (PsyPAG and Association of Internet Researchers), and poster advertisements across Northumbria University campus. Moderators for the Arthritis Research UK, Diabetes UK, and Hope 2 Sleep Facebook groups posted the study advertisement on behalf of the researcher. Participants providing a full response to the survey were entered into a prize draw to win one of ten available shopping vouchers worth £50.00.

All participants were required to be aged at least 18 years and have used the internet to help them make a health related decision. They also should not have taken part in qualitative studies described in Chapters 3 and 4.

Three hundred and forty eight participants started the online survey which was live for 3 months, closing on 31/07/2017. After removing 152 incomplete responses from the data set, complete data was available for N=196 participants. The final sample of participants consisted 46 males and 149 females (1 preferred not to say) who had a mean age of 37.72 years ( $SD= 12.97$ ), and reported using the internet for an average of 16.19 years ( $SD= 5.20$ ) (see Table 6.1 for demographic information). One hundred and twenty one participants (61.70%) completed the survey in relation to a short term health complaint, 75 (38.30%) answered with respect to a long term health complaint.

**Table 6.1.** Demographic information of participants.

		N (%)
<b>Participants</b>	Male	46 (23.50)
	Female	148 (75.50)
	Prefer not to say	2 (1.00)
<b>Ethnicity</b>	Caucasian	168 (85.70)
	Middle Eastern	5 (2.60)
	African	1 (0.50)
	Caribbean	4 (2.00)
	South Asian	3 (1.50)
	East Asian	1 (0.50)
	Mixed	3 (1.50)
	Other	11 (5.60)
<b>Highest Level of Education</b>	Less than High School/ Secondary School	2 (1.00)
	Secondary School	18 (9.20)
	A level or equivalent	15 (7.70)
	Vocational/ technical	9 (4.60)
	High school / GED	7 (3.60)
	College	23 (11.70)
	Bachelor's Degree	51 (26.00)
	Master's Degree	40 (20.40)
	Professional / Doctoral Degree (MD, PhD)	27 (13.80)
	Other	4 (2.00)
<b>Employment status</b>	Full time	82 (41.80)
	Part time	33 (16.80)
	Retired	14 (7.10)
	Unemployed	5 (2.60)
	Student	40 (20.40)
	Other: Homemaker (4), full time mum (3), disabled (6), recovering from op (1), company director (1), self-employed (2), sickness benefits (1), carer (2), medically retired (1), full time sick (3)	22 (11.20)
	<b>Marital Status</b>	Single
Married		83 (42.30)
Cohabiting		33 (16.80)
Civil partnership		4 (2.00)

Table 6.1. continued

Separated	2 (1.00)
Divorced	7 (3.6)
Widowed	1 (0.50)
Other: In a relationship (3)	4 (2.00)

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### 6.2.3 Procedure and materials

This study was granted ethical approval from Northumbria University’s Faculty of Health and Life Sciences Ethical Committee. Participants were provided with a link to the study hosted on Qualtrics. After providing consent, participants started the survey which took approximately 25 minutes to complete. Participants were asked to think about a time when they had used the internet to help them with a health decision when completing the survey. The survey (see appendix 9.13) comprised 6 sections and is described below. Upon completion, participants were presented with a full debrief document and the option to enter their email address to be entered into a prize draw for a chance to win high street gift vouchers as thanks for their time.

#### Survey Measures

The survey items chosen for this study were taken from validated scales and previous literature as discussed below. Alternatively, where the items were developed by research team this is also specified.

*Health complaint context.* Participants were asked to report contextual details regarding their health complaint. Participants provided the length of their health complaint by responding to 2 items; “To what extent would you describe this health complaint as long term?” and “To what extent would you describe this health complaint as short-term?” by selecting one of 5 options; “*a great deal*”, “*a lot*”, “*a moderate amount*”, “*a little*”, “*none at all*”. Participants responded to the statement “What was the main decision you were making” by selecting one of 7 options; “*Treatment related*”, “*Product/ Service related*”, “*Health related administration*”, “*Changing doctor/ doctor surgery/ hospitals*”, “*Diet/ Lifestyle related*”, “*Deciding to have/ not to have further medical tests/ examinations*”, “*Deciding whether to see a Healthcare Professional*”.

*Trust.* Participants also responded to 2 items measuring trust outcomes ‘I trusted the information on the site’ and ‘I trusted the site’ on a Likert scale (1= *strongly disagree*,

7 = *strongly agree*) and significantly were correlated ( $r = .736, p < .001$ ) as in previous research (Harris, Sillence, & Briggs, 2011). For correlation analysis see appendix 9.14).

*Presence of Patient Experiences.* Based on previous research (Sillence, Mo, Briggs, & Harris, 2011; Blythe, Sillence, & Briggs, 2017) the presence of PEx information was assessed with 15 items, for example; “The site contained accounts of other patients experiences”, “There was a chance to share my experiences”, “The personal accounts on the site were written by people similar to me”, “The personal accounts provided social or emotional support”, on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*) (15 items,  $\alpha = .97$ ). Principal Component Analysis (PCA) confirmed all items to load onto one factor “Presence of PEx” (see appendix 9.15 for PCA).

*Empowerment.* The outcomes of Barr et al’s (2015) meta-analysis identified the Genetic Counselling Outcome Scale (GCOS-24) (McAllister et al., 2011) to perform fair-to-good on COSMIN ratings and intermediate to positive on Terwee ratings. Based on previous literature and Study 1 findings, close reading of items suggested a cognitive and affective component.

*Cognitive Empowerment.* Participants responded to 6 items adapted from the GCOS-24 (McAllister et al., 2011) following the stem: The information on the site helped me; “Know what could be gained from each of the options available to me”, “Understand what I can do to change how this issue affects me”, “Know where to go to get the medical help I/my family need” on a Likert scale (1= *strongly disagree*, 7 = *strongly agree*).

*Affective Empowerment.* Based on previous research (Harris et al., 2011; McAllister et al., 2011), 9 items assessed participants affective empowerment, for example; “The information on the site made me feel empowered to do something about my health issue” and following the stem “The information on the site made me feel...”; “Less powerless to do anything about my health issue”, “Empowered to do something about my health issue”, “Able to cope with having this condition/ cope with this health issue” on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*).

*Integration.* This scale was constructed to allow for split responses to the question “Having read the online information did you then decide to go and see a healthcare professional (either straight away or at some point soon afterwards)?”

If participants responded 'YES' they were presented with 17 items, to capture motivations to integrate information in the appointment. Seven of these items were adapted from the Chinese version of the Diabetes Empowerment Process Scale (Chen et al., 2011), e.g.; "My healthcare professional collaborated with me in arriving at my decision", "My healthcare professional considered my knowledge and experience when providing me with information relevant to the decision", "My healthcare professional encouraged me to discuss my concerns/information", "My healthcare professional treated me as an equal rather than as a client" on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*). Participants also responded to 10 items developed by the research team which aimed to investigate how seeking online health information assisted with information integration with healthcare professionals e.g. "The online health information helped me decide to see a healthcare professional", "The online information helped me feel more confident about seeing a healthcare professional", "I wanted to prepare for a visit to the doctors", "I felt the knowledge I brought from the internet supported my discussions with the healthcare professional" on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*). PCA and Cronbach's alpha analyses identified 1 item negatively correlated with the scale "I asked the healthcare professionals questions without revealing I had searched online" and was subsequently removed from the analysis (see section 6.3.2, Table 6.4)

If participants responded 'NO', participants were presented with 14 items to capture reasons underpinning their decision to avoid HCP intervention. Based on previous research (Harris et al., 2011), 6 items measured why participants did not seek HCP appointment; "I didn't want to bother the healthcare professional", "I didn't want to wait for an appointment to become available", "I didn't want to waste the healthcare professional's time", "The doctor did not know much about the health issue" on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*). Participants responded to 8 items that were formulated by the research team; "The information online helped me to decide not to seek further medical help", "I could make the decision on my own without seeing a healthcare professional", "I believe the healthcare professional doesn't want to hear my opinion or consider my knowledge", "I didn't know how to bring up the information" on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*).

*Decision Satisfaction.* Participants responded to 3 items developed by the research team; "I was satisfied with the decision I made", "I was happy with the decision I made",

“I was confident with the decision I made” on a Likert scale (1= *strongly disagree*, 5 = *strongly agree*) (3 items,  $\alpha = .90$ ).

*Demographic information.* Participants provided demographic information including; gender, age, employment status, marital status, ethnicity, educational attainment and years of experience using the internet.

### 6.3 Results

The aims of this study were threefold. The data are presented in relation to each study aim in sections 6.3.2 (aim 1), 6.3.3 (aim 2), 6.3.4 (aim 3). However, first it was first important to examine the overall data pertaining to participant’s health queries and motivations for searching (section 6.3.1).

#### 6.3.1 Overview of participants use of online health information

Table 6.1 (above) shows that participants in this study were mostly; female (75.50%), Caucasian (85.70%), worked full time (41.80%), were married (42.30%) and more than half had a bachelor’s degree qualification or higher (60%). Table 6.2 provides a breakdown of participants’ self-reported health condition characteristics. This descriptive table shows participants were largely completing the survey with reference to a short term health issue (61.70%) as opposed to a long term health issue (38.30%). Participants reported mainly using online health information to help them make a treatment related decision (35.20%) or to help decide whether or not to see an HCP (32.10%). The information search was conducted to gain a broader perspective about the health condition (42.90%) and to gain information from other people about the condition (25.50%).

**Table 6.2.** Breakdown of participants’ health condition characteristics, decision types and motivations for online health searching.

		Frequency (%)
Duration of health issue	Long Term Health Issue	75 (38.30)
	Short Term Health Issue	121 (61.70)
To what extent did you consider this health issue to be serious?		103 (52.60)
To what extent did you consider this health issue to be sensitive?		126 (64.30)

Table 6.2. continued

What was the main decision you were making?	Treatment related	69 (35.20)
	Product/ service related	11 (5.60)
	Health related administration	6 (3.10)
	Changing Doctor/ doctor surgery/ hospitals	1 (0.50)
	Diet/lifestyle related	25 (12.80)
	Deciding to have/not to have further medical tests/examinations	21 (10.70)
	Deciding whether to see a healthcare professional	63 (32.10)
	What was the main motivation for searching online to support your decision making?	Someone told me to
Health professional told me to		6 (3.10)
To find information from other people		50 (25.50)
To double check information		35 (17.90)
To see more options		17 (8.70)
Who do you think owns the website?	To get a broader perspective	84 (42.90)
	NHS or Government	96 (49.0)
	Charity	39 (19.9)
	Commercial organisation	28 (14.30)
	Pharmaceutical manufacturers	11 (5.60)
	Education institution	5 (2.60)
	Health insurance group	3 (1.50)
Other	14 (7.10)	

### 6.3.2 Aim 1 findings

- (1) Explore any differences how individuals with short term and long term health conditions use the internet to support health

Chi squared analyses (see Table 6.3) were conducted to examine whether condition length (long term or short term) was associated with visiting an HCP after reading online health information.

**Table 6.3.** Contingency table showing how many participants with long and short term health conditions visited their healthcare professional after reading online health information (N=196).

		<b>HCP Yes</b>	<b>HCP No</b>
<b>Condition Duration</b>	Long Term	48 (64%)	27 (36%)
	Short Term	93 (76%)	28 (24%)

Of the participants who reported answering the survey in reference to a long term health condition, 64% went to see a HCP having read online health information, in comparison to 76% of respondents with short term conditions. Chi squared analysis identified an association between the variables Condition Duration and HCP visit that was approaching significance,  $\chi^2(1) = 3.79, p = 0.051$ . Cramer's  $V = .139; p < 0.01$  indicates a small effect size.

### **Differences in condition duration and information type**

Findings reported in Chapter 3 indicated individuals with long term health complaints preferred for PEx information to support their health decisions. The present study therefore explored who (participants with either long term or short term health conditions) viewed PEx information in their online health information searching.

An independent samples t-test showed that individuals with short term health condition ( $M = 3.01, SD = 1.20$ ) reported seeing significantly more PEx information than those with long term conditions ( $M = 2.58, SD = 1.05$ ),  $t(194) = 2.561, p = .011$ . Cohens  $d = 0.38$  indicates a small-to-medium effect size.

### **Decision Satisfaction**

Thus far, findings have demonstrated that participants with long term and short term health conditions consult different types of health information, and differentially act upon health information, when making a health decision. It was therefore of interest to understand whether these two groups differed in their overall decision satisfaction.

An independent samples t-test revealed no significant difference in decision satisfaction scores between individuals completing the survey in relation to a short term health complaint ( $M = 4.37, SD = 0.70$ ) than individuals completing the survey in relation to a

long term health complaint ( $M= 4.26, SD= 0.79$ ),  $t(194)=1.029, p = .305$ . Cohens  $d = 0.15$  indicates a small effect size.

### *Summary*

Overall, these findings suggest that participants used online health information to inform a multitude of health decisions. Results also show that individuals with long term and short term health conditions differ in their the type of information they saw, and their decision to see a HCP after the online searching, however they did not differ in reported decision satisfaction.

### **6.3.3 Aim 2 findings**

- (2) Examine reasons underpinning decisions to integrate, or not integrate online health information into appointments with HCPs

This study was also interested to investigate how participants acted upon information sourced from their internet searching. Specifically, whether participants consulted with a HCP after their online health information searching and if so why? To address this aim, participant responses were explored using PCA to investigate motivations for choosing to consult with an HCP, or avoid seeing an HCP after their online health information searching. Repeated measure Analyses of Variance (ANOVA) and one sample t-tests were then employed to identify salient motivations to seek or avoid HCP intervention.

### **Participants who saw a HCP**

Of the 196 participants who completed the survey, 141 decided to see a HCP after reading the online information. PCA (with orthogonal varimax rotation) was conducted on the 16 item integration scale, which explored participants' motivations to seek an appointment with a HCP. The Kaiser-Meyer-Olkin (KMO) measure verified the sampling adequacy for the analysis,  $KMO = .826$  which is considered "great" (Hutcheson & Sofroniou, 1999). Bartlett's test of sphericity  $\chi^2(120) = 1339.333, p < .001$ , indicated that correlations between items were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues for each component of the data. Three components had eigenvalues over Kaiser's criterion of 1 and in combination explained 64.83% of the variance. The scree plot showed inflexions that justified retaining components 1, 2 and 3. Given the sample size, the convergence of the scree plot and Kaiser's criterion on three components, this is the number of components that were retained in the final analysis. Table 6.4 shows

the factor loadings after rotation, coefficients below .3 were suppressed. The items that cluster on the same components suggest that component 1 represents *Healthcare Professionals Encouragement*, component 2 represents *Patient Contribution*, and component 3 represents *Visit Focussed Preparation*.

The first component tentatively named ‘*Healthcare Professionals Encouragement*’ describes the positive reaction from the HCP when participants integrated online health information into the appointment, welcoming and encouraging discussions and collaborating on a decision. The second component tentatively named ‘*Patient Contribution*’, details the patient’s actions when integrating online health information into the appointment, and describes how information was integrated and patients evaluation of its contribution to the appointment. The third component tentatively named ‘*Visit focused Preparation*’ describes patients online searching to prepare for the appointment. These constructs suggest that participants were motivated by three key constructs to consult with an HCP after their online health information search.

**Table 6.4.** Summary of exploratory factor analysis for participants responses to the scale measuring information integration in healthcare appointments (N=141).

	Rotated Factor Loadings		
	Healthcare Professionals Encouragement	Patient Contribution	Visit Focussed Preparation
The online health information helped me decide to see a healthcare professional			<b>.840</b>
The online health information helped me feel more confident about seeing a healthcare professional			<b>.829</b>
I wanted to prepare for a visit to the doctors			<b>.632</b>
I told the healthcare professional that I had searched online for information		<b>.765</b>	
I brought the information I found online to the appointment with the healthcare professional		<b>.799</b>	
I felt the knowledge I brought from the internet supported my discussions with the healthcare professional		<b>.827</b>	

Table 6.4. continued

My knowledge from the internet positively supported the communication between myself and the healthcare professional		<b>.729</b>
I asked the healthcare professional questions based on the internet information		<b>.586</b>
My healthcare professional considered my knowledge and experience when providing me with information relevant to the decision	<b>.719</b>	320
The information provided by my healthcare professional was necessary to help my decision making	<b>.660</b>	
My healthcare professional treated me as an equal rather than as a client	<b>.880</b>	
My healthcare professional listened to me attentively and patiently	<b>.918</b>	
My healthcare professional encouraged me to discuss my concerns/information	<b>.858</b>	
My healthcare professional made me feel at ease when discussing my concerns and fears	<b>.914</b>	

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One sample t-tests showed that mean Visit Focussed Preparation scores ( $M= 4.13$ ,  $SD= 0.71$ ) were significantly higher than the normal score of 3,  $t(140) = 18.996$ ,  $p < .001$ . Mean Patient Contribution scores ( $M= 3.30$ ,  $SD= 0.99$ ) were significantly higher than the normal score of 3,  $t(140) = 3.571$ ,  $p < .001$ . Mean Healthcare Professionals Encouragement scores ( $M= 3.73$ ,  $SD= 0.94$ ) were significantly higher than the normal score of 3,  $t(140) = 9.201$ ,  $p < .001$ . These findings show that for participants who did see a HCP, online health information mainly helped them to prepare for the appointment, but integration was also encouraged through contributing to the appointment, and gaining encouragement from the HCP.

A repeated measures ANOVA with post hoc comparisons was conducted to compare scores on these three factors. Wilks' Lambda = .579,  $F(2,139) = 50.545$ ,  $p < .001$ ,  $\eta^2 = .421$ . For those who reported making an appointment with their HCP after reading online

health information, the information was significantly more useful in respect to preparing for the visit (visit focussed preparation,  $M= 4.13$ ) in comparison to patient contribution ( $M= 3.30$ ,  $p < .001$ ) and healthcare professionals contribution ( $M= 3.73$ ,  $p < .001$ ), and healthcare professionals encouragement was significantly more useful than patient contribution ( $p < .001$ ).

### **Participants who did not see a HCP**

Of the 196 participants who completed the survey, 55 decided not to see a HCP after reading the online information. Participants who did not seek help from a HCP completed a different scale to participants who did report seeing a HCP. A PCA (with orthogonal varimax rotation) was conducted on the 14 item scale which explored participant's motivations to not seek an appointment with a HCP after their online searching. The Kaiser-Meyer-Olkin (KMO) measure verified the sampling adequacy for the analysis,  $KMO = .627$  which is considered "mediocre" (Hutcheson & Sofroniou, 1999). Bartlett's test of sphericity  $\chi^2 (91) = 394.292$ ,  $p < .001$ , indicated that correlations between items were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues for each component of the data. Four components had eigenvalues over Kaiser's criterion of 1 and in combination explained 71.97% of the variance. The scree plot showed inflexions that justified retaining components 1,2,3 and 4. Given the sample size, the convergence of the scree plot and Kaiser's criterion on four components, these were retained in the final analysis. Table 6.5 shows the factor loadings after rotation, coefficients below .3 were suppressed. The items that cluster on the same components suggest that component 1 represents *Solo Decision Making*, component 2 represents *Integration Worries*, component 3 represents *Beliefs about the HCP*, and component 4 represents *Avoid being a burden*.

The first component tentatively named '*Solo Decision Making*' describes that online health information helped participants feel confident to make a health related decision independently, without requiring a consultation with a HCP. The second component tentatively named '*Integration Worries*' describes participants' lack of confidence and knowledge regarding how to bring up the topic of their information searching. The third component tentatively named '*Beliefs about the HCP*' describes participants' lack of trust in the HCP and their perception that the HCP does not want to hear about their information searching. The final component tentatively named '*Avoid being a burden*' describes participants' efforts to avoid wasting the HCPs time or resources. These

constructs highlight four key motivations underpinning participants' decisions not to see an HCP following their online health information search.

**Table 6.5.** Summary of exploratory factor analysis results for participants responses to the scale measuring HCP avoidance (N=55).

	<b>Rotated Factor Loadings</b>			
	Solo Decision Making	Integration Worries	Beliefs about the HCP	Avoid being a burden
The information online helped me to decide not to seek further medical help	<b>.657</b>	-.306		
I could make the decision on my own without seeing a healthcare professional	<b>.826</b>			
I felt confident to make the decision on my own	<b>.826</b>			
I felt confident to make the decision after reading the online information	<b>.825</b>			
I didn't want to bother the healthcare professional				<b>.851</b>
I didn't want to wait for an appointment to become available				<b>.609</b>
I didn't want to waste the healthcare professional's time				<b>.866</b>
The doctor did not know much about the health issue	-.350		<b>.763</b>	
I did not trust the doctor		.329	<b>.796</b>	
I believe healthcare professional doesn't want to hear my opinion/ consider my knowledge		.387	<b>.705</b>	
I didn't know how to bring up the information		<b>.845</b>		
I didn't feel confident to discuss the information	-.450	<b>.766</b>		
I felt embarrassed		<b>.802</b>		
I didn't want them to know I had searched online		<b>.747</b>	.316	

One samples t-test showed that mean Solo Decision Making scores ( $M= 4.01, SD= 0.85$ ) were significantly higher than the normal score of 3,  $t(54) = 8.798, p < .001$ . Mean scores for Avoid Being a Burden ( $M= 3.11, SD= 1.09$ ) were significantly higher than the normal score of 3,  $t(54) = 0.743, p = .461$ . Mean scores for Beliefs About The Healthcare Professional ( $M= 2.35, SD= 1.03$ ) were significantly lower than the normal score of 3,  $t(54) = -4.711, p < .001$ . Mean scores for Integration Worries ( $M= 2.15, SD= 1.08$ ) were significantly lower than the normal score of 3,  $t(54) = -5.785, p < .001$ . These findings show that participants who did not see a HCP, were mostly using online health information to help them make a decision alone, but beliefs about the HCP, worries about integration, and avoiding being a burden also contributed to decision to avoid seeking an appointment with a HCP.

A repeated measures ANOVA with post hoc comparisons was conducted to compare scores on these three factors, Wilks' Lambda = .391,  $F(3,52) = 27.000, p < .001, \eta^2 = .609$ . For those who did not make an appointment with their HCP after reading online health information, the information was significantly more useful in respect to making a decision without HCP intervention (solo decision making,  $M= 4.01$ ) in comparison to avoid being a burden ( $M = 3.11, p < .001$ ), beliefs about the HCP ( $M= 2.35, p < .001$ ), and integration worries ( $M= 2.15, p < .001$ ). The information was significantly more useful in respect to avoid being a burden than due to beliefs about the HCP ( $p < .05$ ) and integration worries ( $p < .001$ ). Beliefs about the HCP was not significantly more useful than integration worries ( $p = 1.00$ ).

#### **6.3.4 Aim 3 findings**

- (1) Use mediation analyses to explore pathways linking PEx, trust, and empowerment to decision satisfaction

The primary aim of the present study was to use mediation analyses to explore pathways linking PEx, trust, and empowerment to decision satisfaction. Prior to conducting mediation analyses, PCA applied to empowerment measures confirmed the presence of three constructs; *cognitive empowerment* (5 items,  $\alpha= .802$ ), *positive affective empowerment* ( $n=7, \alpha= .841$ ), and *negative affective empowerment* ( $n= 3, \alpha= .723$ ). Table 6.6 shows the factor loadings after rotation, coefficients below .3 were suppressed.

**Table 6.6.** Summary of exploratory factor analysis for participant responses on empowerment scale (N=196).

	Rotated Factor Loadings		
	Negative Affective Empowerment	Positive Affective Empowerment	Cognitive Empowerment
The information on the site made me feel... -Powerless to do anything about my health issue	<b>-.727</b>		-.338
The information on the site made me feel... -Worried	<b>-.702</b>	-.309	
The information on the site made me feel... -Confused	<b>-.790</b>		
The information on the site made me feel... -Empowered to do something about my health issue	.458	<b>.423</b>	.363
The information on the site made me feel... -More positive about making future decisions about my health	.400	<b>.590</b>	
The information on the site made me feel... -Able to cope with having this condition/ cope with this health issue		<b>.623</b>	
The information on the site made me feel... -Reassured	.336	<b>.651</b>	
The information on the site made me feel... -Optimistic		<b>.752</b>	
The information on the site made me feel... -In control		<b>.676</b>	
The information on the site helped me...-Explain what the issue means to others		<b>.682</b>	

Table 6.6. continued

The information on the site helped me...-Know where to go to get the medical help I/my family need		<b>.785</b>
The information on the site helped me...-Know what could be gained from each of the options available to me		<b>.662</b>
The information on the site helped me...-Understand the reasons behind my health professionals' suggestions		<b>.635</b>
The information on the site helped me...-Understand what I can do to change how this issue affects me		<b>.759</b>
The information on the site helped me...-Make plans for the next steps/ decisions	.345	<b>.674</b>

### **Associations between variables**

Correlation analyses (see Table 6.7) indicated that trust and PEx were positively associated with decision satisfaction. Trust and PEx was positively associated with cognitive empowerment and positive affective empowerment, but were negatively associated with negative affective empowerment. Decision satisfaction was positively correlated with cognitive empowerment and positive affective empowerment, but negatively associated with negative affective empowerment.

**Table 6.7.** Descriptive statistics and correlations between IVs, DVs, and Mediators

		Correlations					
	<i>M (SD)</i>	1	2	3	4	5	6
Independent variables							
1. Trust	6.06 (0.90)	-					
2. PEx	2.84 (1.16)	-.040	-				
Dependent variable							
3. Decision satisfaction	4.33 (7.36)	.317**	.115	-			
Mediators							
4. Cognitive empowerment	3.92 (0.64)	.370**	.211**	.437**	-		
5. Positive affective empowerment	3.81 (0.66)	.302**	.375**	.460**	.658**	-	
6. Negative affective empowerment	2.29 (0.86)	-.311**	-.144*	-.415**	-.362**	-.546	-

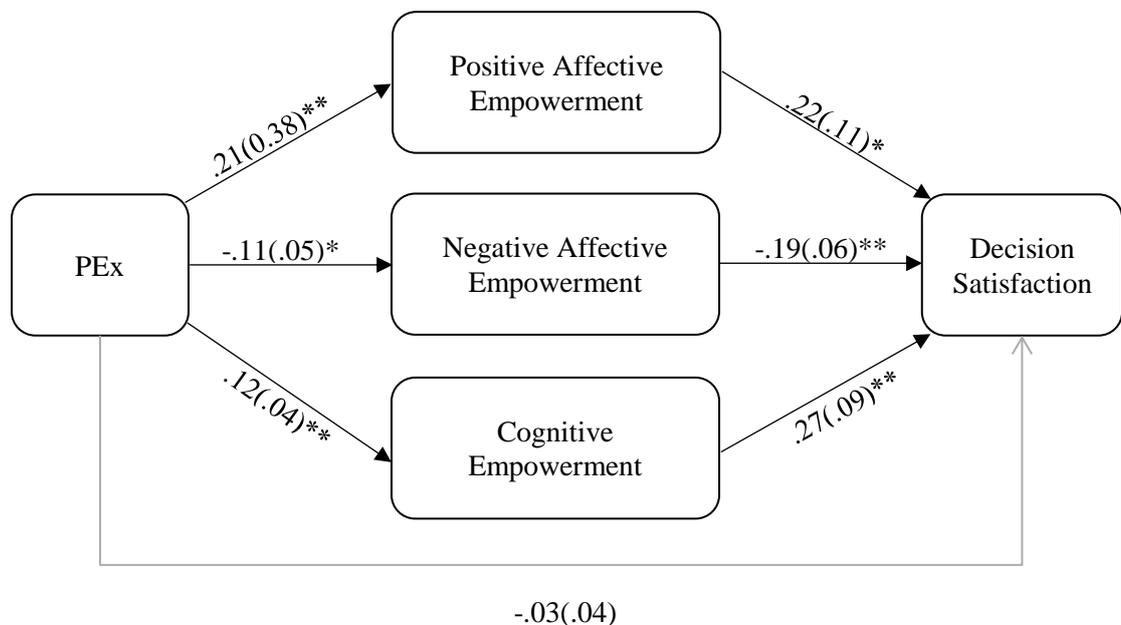
\* $p < .05$ . \*\* $p < .001$

### Indirect effects

Given that some forms of empowerment had significant effect on trust and PEx, and that these predicted decision satisfaction (see Table 6.7 above) there was a possibility of an indirect effect of trust and PEx on decision satisfaction via empowerment (Baron & Kenny, 1986; MacKinnon, 2012; Preacher & Hayes, 2008). Indirect effect analyses were performed using the Process macro for SPSS (Model 4, Hayes, 2013) to test mediation. In these analyses decision satisfaction was the dependent variables, PEx and Trust were the independent variables, cognitive and affective empowerment were mediating variables. The confidence intervals were calculated using 5000 bootstrap resamples, and a 95% confidence interval. For the first 2 analyses Model 4 was employed. See appendix 9.16 for mediation output data.

## PEx Information

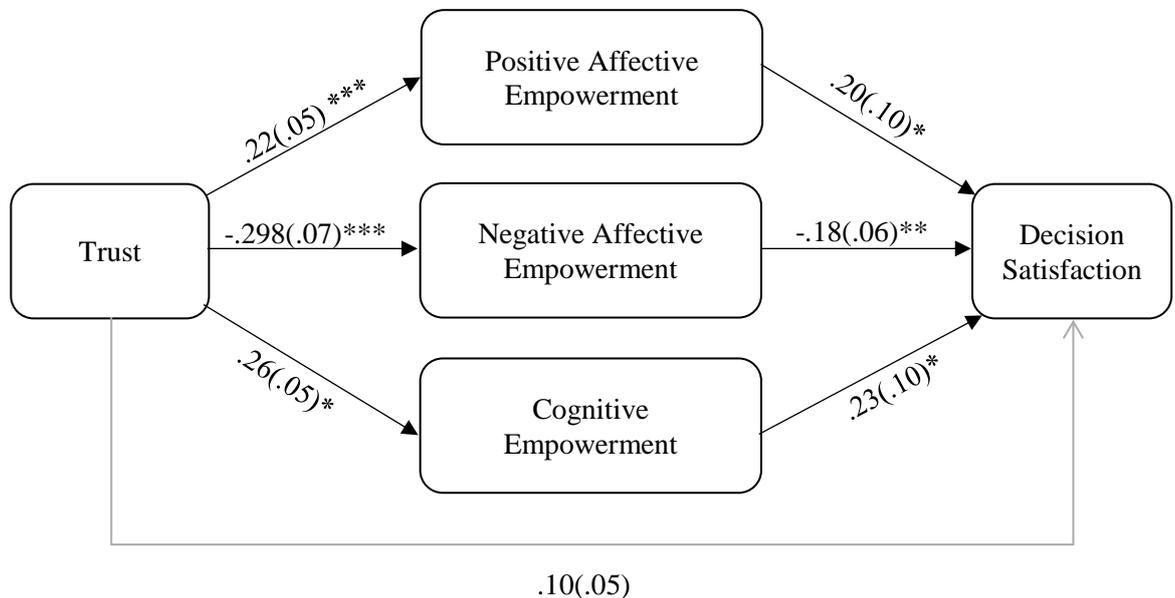
The indirect effect analysis revealed that the significant effect of PEx on decision satisfaction became non-significant after controlling for empowerment (see Figure 6.1). This analysis also revealed that positive affective empowerment, negative affective empowerment, and cognitive empowerment, each uniquely predicted decision satisfaction whilst controlling for the other variables. Indeed, 95% confidence intervals did not contain zero (i.e., were significant) for the indirect effect via positive affective empowerment ( $B = .05$ ,  $SE = .02$ , 95% CI [.01, .09]), negative affective empowerment ( $B = .02$ ,  $SE = .01$ , 95% CI [.00, .06]), and cognitive empowerment ( $B = .03$ ,  $SE = .02$ , 95% CI [.01, .07]). These results suggest that reading PEx information had an indirect effect via positive affective empowerment, negative affective empowerment, and cognitive empowerment. These results suggest that reading PEx positively predicted feelings of positive affective empowerment and cognitive empowerment, which positively predicted decision satisfaction. In turn, reading PEx information also negatively predicted feelings of negative affective empowerment, which negatively predicted decision satisfaction. This means that participants who obtain positive feelings, or believe to have gained knowledge from reading PEx health information become satisfied with their health decision. On the other hand, participants who gain negative feelings of worry and concern after reading PEx health information feel less satisfied with their health decision.



**Figure 6.1.** The indirect effect of PEx information on health decision satisfaction via empowerment pathways. The values represent unstandardised betas and standard errors (in brackets). Pathways were regarded as significant if the p-value was below .05\*, <.01\*\*, <.001\*\*\*

## Trust

The indirect effect analysis revealed that the significant effect of trust on decision satisfaction became non-significant after controlling for empowerment (see Figure 6.2). This analysis also revealed that positive affective empowerment, negative affective empowerment, and cognitive empowerment, each uniquely predicted decision satisfaction whilst controlling for the other variables. Indeed, the 95% confidence intervals did not contain zero (i.e., were significant) for the indirect effect via positive affective empowerment ( $B = 0.4$ ,  $SE = 0.2$ , 95% CI [.01, .10]), negative affective empowerment ( $B = 0.5$ ,  $SE = .02$ , 95% CI [.02, .11]), and cognitive empowerment ( $B = .06$ ,  $SE = .03$ , 95% CI [.01, .13]). These results suggest that perceived website and information trust positively predicted feelings of positive affective empowerment and cognitive empowerment, which positively predicted decision satisfaction. In turn, perceived website and information trust negatively predicted feelings of negative affective empowerment, which negatively predicted decision satisfaction. This means that trust increased positive feelings of empowerment and cognitive empowerment, which increased decision satisfaction. However, lower trust predicted negative feelings of empowerment, which negative predicted decision satisfaction.



**Figure 6.2.** The indirect effect of website trust on health decision satisfaction via empowerment pathways. The values represent unstandardised betas and standard errors (in brackets). Pathways were regarded as significant if the p-value was below .05\*, <.01\*\*, <.001\*\*\*

## **Covariates**

The above indirect analyses were repeated with trust and PEx as covariates. The effects reported above remained after controlling for these covariates. This suggests that the indirect effect of PEx was not due to perceived information and website trust, and vice versa.

## **6.4 Discussion**

The present study sought to address three main aims. The discussion of findings are presented in relation to these aims.

### **(1) Explore any differences in how individuals with short term and long term health conditions use the internet to support health decisions**

As qualitative interviews with individuals with long term and short term health conditions in Chapters 3-4 identified differential use of the internet for health related decision making, this study also aimed to explore these differences with a larger more diverse sample. Interestingly, the present study results showed that a greater percentage of participants with short term health complaints than long term complaints attended an HCP appointment after consulting online health resources. Conceptually, this is understandable given that the majority of participants with short term conditions were primarily making a treatment related decision, which often requires HCP intervention in order to receive a treatment prescription. These findings were also noted in Chapter 4, where individuals with short term conditions were mostly motivated to understand the cause of their ill health and to source a treatment, which often prompted seeking HCP intervention. In Chapter 3, participants with long term conditions mostly reported using online health information for social support and to keep updated with emerging treatment ideas and therapies, however in the present study participants with long term conditions primarily consulted the internet information to help them decide whether to seek HCP intervention. These conflicting findings are perhaps attributable to the varying severity and illness trajectories associated with chronic, long term health conditions. It is likely that initial stages in chronic health conditions involve a multitude of decisions which become fewer as time progresses, whilst later phases may require more condition management and support. Therefore, these differences may be due to participant differences between the present study and Chapter 3.

Individuals with short term conditions reported seeing significantly more PEx information than those with long term health conditions. These findings are interesting

given that earlier qualitative work reported that PEx was the preferred resource for individuals with long term conditions (Chapter 3). This finding may be explained by the number of health websites that now typically include a balance of static and PEx information, given that research findings highlight the usefulness of both information types in health decision making (Zebregs et al., 2015). For example, though understood as a static, factual information resource, the NHS Choices website content incorporates patient videos, stories and links to support groups. PEx information is thus becoming increasingly embedded within traditional, static information sites, making the ability to distinguish static sites from PEx more difficult for participants. These findings allude to the amalgamation of different information types on health websites, which may preclude participants' judgements in determining what information they have seen.

Overall, these novel findings identify interesting differences in the ways in which individuals with long term and short term health complaints differentially use and integrate online health information in their health decision making. Despite these differences, results show no significant differences in participants reported satisfaction with their health decision. Findings also suggest that as illness trajectories progress, patients' needs and information sourcing subsequently change, thus information searching evolves with the progression of the health condition. Future research should consider mapping how use of online health information resources develop across illness trajectories, in order to specify pertinent information at different stages.

## **(2) Examine reasons underpinning decisions to integrate, or not integrate online health information into appointments with HCPs**

As previous literature and findings in Chapters 3-5 identify a juxtaposition between the HCP and patient expectations regarding information integration in appointments, this study sought to examine reasons why participants felt able or unable to disclose and discuss their online health information searching with a health professional. For participants who decided to see a HCP after their online health information searching, three key factors contributed to their decision to integrate the information. Responses to the survey indicated that participants mainly used their online health searching in preparation for the consultation to enhance knowledge and develop skills to effectively communicate and collaborate with the HCP and contribute to the discussion. These findings sustain those of prior research that also identifies patients search online to prepare for an appointment (Caiata-Zufferey et al., 2010), and support findings reported in this thesis, where participants described preparing for appointments in order to be on a

similar level of understanding with the HCP (Chapter 3), and in order to efficiently converse with the HCP to gain a swift diagnosis (Chapter 4). Furthermore, in Chapter 5, HCPs encouraged internet informed patients to integrate their information into discussions, recognising that dismissing such attempts to be involved in their own care can negatively impact the professional-patient relationship and consultation. Similarly, the present study identified that a positive response from the HCPs encouraged participants' intentions to integrate online health information.

Four main motivations underpinned participants' decision not to see an HCP after their online health information searching. Results showed that online health information was mostly consulted in order for participants to gain enough information to be able to inform and make their own decision without requiring HCP intervention. This finding speaks to those discussed in Chapter 4, whereby participants reported using the internet as a triage device that directs individuals to or away from HCP assistance. The use of the internet to support health decisions external to the medical appointment provides evidence in support of the notion of DDM (Rapley, 2008). Chapters 3-5 highlighted a discordance between patients understanding of HCP's beliefs about internet informed patients, and HCP's actual beliefs. Given the current emphasis to involve patients in healthcare, these findings raise a timely issue affecting patient involvement in care decisions that must be addressed and investigated further.

### **(3) Use mediation analyses to explore pathways linking PEx, trust, and empowerment to decision satisfaction**

The primary aim of the present study was to investigate pathways through which participants achieved satisfaction with their health decision as a result of their online health information searching. The present study highlights 2 mediation models. The first model tested relationships between PEx information, positive affective empowerment, negative affective empowerment, cognitive empowerment, and decision satisfaction. Positive affective empowerment significantly mediated the pathway from PEx and decision satisfaction. This result confirms previous literature and discussions in Chapters 3 and 4, where participants reported feeling less anxious and lonely but more socially supported after engaging with PEx information (Coulson & Shaw, 2013; Mo & Coulson, 2014). However, negative affective empowerment mediated a significant negative relationship between PEx and decision satisfaction. The evaluative valence of PEx message content can vary from extremely positive to extremely negative, which, according to Shaffer and Zikmund-Fisher (2012), can influence decisions by inducing

different information processing routes. In particular, message valence can affect decision making through changes in mood elicited by the message content (Clore & Huntsinger, 2007). This idea can be applied to understand the present study findings, for example, positive PEx information can induce feelings of confidence and contentedness regarding making a certain health decision, these positive feelings contribute to the ‘positive affective empowerment’ which brings about increased satisfaction with a decision. Likewise, PEx that induces negative emotions of worry and concern can trigger negative feelings or ‘negative affective empowerment’ which may cause anxiety regarding making a particular health decision that may be considered unsatisfactory. The present mediation model also identified cognitive empowerment to positively and significantly mediate the pathway between PEx and decision satisfaction. Cognitive empowerment describes the process through which new knowledge and information empowers and supports decision making, and corroborates those in previous literature and Chapter 3, where participants described knowledge acquired from PEx information, such as treatments, products, and decisions of which they were previously unaware of (Entwistle & Watt, 2006), enabled them to feel informed and thus empowered to make decisions. It seems that PEx information enables readers to consider what it is like to make a certain decision, and knowing that others have made the choice helps the reader to feel more confident and perhaps more satisfied with their decision.

The second model tested relationships between trust, positive affective empowerment, negative affective empowerment, cognitive empowerment, and decision satisfaction, and identified a similar pattern of findings to the first model. Positive affective empowerment and cognitive empowerment positively mediated the association between trust and decision satisfaction, whilst negative affective empowerment negatively mediated the relationship between trust and decision satisfaction. Given that trust is associated with information engagement (Sillence et al., 2014) and likelihood to act on advice (Wang et al., 2008), it is conceivable that trustworthy information positively affects cognitive and positive affective empowerment, as participants think and feel positively about the information and are consequently more satisfied with their decision knowing it was based upon trustworthy information. Similarly, low perceptions of website and information trust bring about negative thoughts, such as feeling anxious or worried (negative affective empowerment), which in turn significantly predicted lower levels of decision satisfaction.

The mediation analyses present two key novel and interesting findings. Firstly, results show the pervasive role of ‘feelings’ (affect) in health decision satisfaction. Traditional

models of decision making were developed from theories of cognitive and rational thinking, do not consider the role of emotion in decision making (as discussed in Chapter 2, Literature Review). Secondly, the findings show that trust has a particularly positive effect on how participants felt and thought about their health decisions, this is perhaps due to the fact that trust is a psychological state (Kim, 2016). Thus, the perceived trustworthiness of a website/ information can influence emotional affect, and contributes to decision satisfaction or dissatisfaction.

#### **6.4.1 Conclusion**

This chapter reports a number of interesting and novel findings. Firstly, that cognitive and affective aspects of empowerment mediate the relationship between PEx and website/ information trust, and decision satisfaction. The findings also substantiate those presented earlier in this thesis, i.e. that individuals with short term health conditions are more likely to see an HCP after online searching than individuals with long term health conditions. Secondly, the study presents a more detailed explanation underpinning participants' decisions to see, or not to see an HCP after their online searching. Overall, the findings highlight the integrated nature of health decision making, by identifying the influence of different information sources, and pathways through which these affect decision satisfaction. Finding thus provide evidence for Rapley's (2008) notion of DDM.

#### **6.4.2 Strengths and limitations**

This survey asked participants to consider an occasion where they have used online health information to help them with a health decision. The retrospective nature of the task relies upon the participant's memory to recall a specific website they considered instrumental in helping them with their choice. Given that this thesis emphasises the need to consider health decision making from a distributed perspective i.e. that interactions with people and technologies over time, it is most likely a person's decision was informed by interactions with multiple website and e-Health sources, which this cross sectional study design does not capture. Therefore, future research should employ 'show and tell' methodologies which allow the participant to show how they search and use online health information, and describe how they evaluate its trustworthiness (Lee et al., 2016) to overcome this limitation.

Empowerment has been defined and measured in innumerable ways throughout established literature. A prominent strength of this study was the careful selection of empowerment scales that perform well on strict criteria (Barr et al., 2015), and were

checked using factor analyses and reliability analyses to ensure they functioned as intended.

## **6.5 Chapter summary**

This chapter described a quantitative survey designed to expand qualitative findings discussed in Chapters 3-4 across a larger sample representing more health conditions and decision types. The key findings corroborate findings to suggest that individuals with long term and short term health conditions differ in their searching motivations, information preferences, and integration behaviour. This study is thus novel, as to date no previous research has simultaneously considered and compared how individuals with differing conditions use the internet as a decision support tool. The study further contributes to knowledge as findings identify two key pathways through which participants achieve decision satisfaction, through online health information searching. These preliminary findings warrant further investigation to disentangle what aspects of trust contribute to decision satisfaction, and further investigate whether different types of narrative information (e.g. process, experience, and outcome) affect decision satisfaction.

Findings reported here and in previous chapters, suggest a conflict in participants understanding about HCPs perspectives about information integration, and HCPs actual perspectives. This misunderstanding has prevented individuals from seeking HPC intervention, and from integrating the information into the appointment. Given the importance placed upon patient participation in healthcare and health decisions, it is important to consider how to encourage and facilitate the integration of online health information into medical appointments. As the present study findings identify PEx plays a central role in health decisions and decision satisfaction, the next chapter aims to manipulate PEx information, to try to improve intentions to integrate online health information into discussions with the HCP.

## **Chapter 7: Experimental investigation to influence patient intentions to integrate online sourced health information to a healthcare professional (Study 5)**

This chapter describes the findings of a hypothetical treatment decision making task, focussing on increasing intentions to discuss PEx information with HCPs. PEx information is a popular and persuasive information source, which appears to contribute to decision satisfaction by acting upon affective aspects of empowerment (Chapter 6). However, patients are hesitant to raise and discuss PEx information with HCPs (Chapters 3 and 4) despite HCPs encouragement (Chapter 5). Given that PEx information is a popular and potentially empowering information resource, but one that causes particular difficulties for HCP discussions, this chapter details an experimental study utilizing a hypothetical treatment decision making task in order to investigate whether manipulations of PEx health information presented on a health information website could affect intentions to discuss PEx information with a HCP.

### **7.1 Introduction**

The term “PEX” or “Patient experiences” describes a constructed narrative or story which the author has experienced. Chapter 2 describes the use and value of patient narratives within health information provision and its role in health decision making. For example, PEx information has the ability to evoke emotional responses to messages and transport the reader into a narrative world (Green & Brock, 2002), and has been shown to positively impact upon behavioural intentions to vaccinate against Hepatitis B (De Wit et al., 2008) and HPV (Murphy, Frank, Chatterjee, & Baezconde-Garbanati, 2013), reduce tanning bed use (Greene & Brinn, 2003), positively impact smoking cessation (Kim, Bigman, Leader, Lerman, & Cappella, 2012), and improve mammography screening uptake (Kreuter et al., 2010; McQueen & Kreuter, 2010).

However, there are concerns around the potentially biasing effects of PEx health information on beliefs, attitudes and intentions (Zebregs et al. (2015). Narrative messages require little attention and cognitive effort to process (Kreuter et al., 2007; Kreuter et al., 2010) and encourage simplistic heuristic information processing rather than the slower systematic processing used for processing factual and statistical information (Winterbottom et al., 2008). A particular concern expressed by many HCPs is that patients may form health decisions on misinformation (Ahmad et al., 2006).

In their model of patient engagement, Sillence et al. (2014), propose that users engage with PEx information through three different processes: gaiting, the engagement loop, and evaluation. In the first, users make rapid judgements about the initial appearance of the information site based on the website's reputation and design. In the engagement loop process (also referred to as the relevance phase), users examine the website and PEx content in further detail, and consider who is providing the information, what the information says, and engage in a process of self-reflection by assessing how the stories compare with their own experiences before making an assessment of the information credibility. For example, when considering the author and the information content, users reject accounts that stem from authors who are dissimilar from themselves e.g. different age and condition severity, or authors that recount experiences that are unfamiliar or distant. A preference for sourcing PEx from authors who are similar in outlook or experience is also reported in previous research (Fox & Duggan, 2013). Within this model, the relevance phase can lead to decision making and behaviour change. The present study thus investigates whether prompts to engage in self-reflection of this kind around the PEx information on a health website, can increase patient intentions to discuss PEx information with their HCP.

Patients increased involvement in healthcare epitomises a shift from the traditional model of paternalism to a one of mutual participation and shared health decision making (Townsend et al., 2015). This change in roles has prompted researchers to consider the potential implications of integrating internet sourced information (e.g. PEx) into appointments and consultations with HCPs. Though early work in this area reports negative HCP attitudes (Ahmad et al., 2006), positive perspectives continue to emerge from more current research (Macdonald et al., 2018) and are also detailed within this thesis (Chapter 5).

Despite the concerns surrounding the persuasive impact of PEx on health behaviour and decisions, it remains an important information resource for many individuals, particularly those with longer-term health conditions (Thackeray et al., 2013). Previous chapters highlight the mediating role of PEx information on health decision satisfaction (Chapter 6), and has highlighted the integration and discussion of PEx information with HCPs to be a contentious issue (Chapters 3-5). In Chapters 3 and 4, patients reported barriers to discussing PEx information with HCPs which corroborates previous literature (Joseph-Williams et al., 2014; Silver, 2015; Tan & Goonawardene, 2017), for example, feeling embarrassed, or unsure how to raise PEx information with HCPs. However, in Chapter 5

HCPs encouraged patients to be transparent in discussing their online health searching, describing this to be of benefit to the consultation and suggested ways in which patients could introduce the information more effectively into the consultation. Considering the popularity of PEx in health decisions and the incongruent views between the patient and health professional pertaining to the integration of this type of information into appointments or consultations, the present study investigates whether a ‘discussion starters’ prompt, accompanying the PEx information presented on a health website can increase intentions to discuss PEx information with an HPC. The present study will also examine the impact of PEx on decision satisfaction, given that Chapter 6 showed that PEx predicted decision satisfaction (Chapter 6).

### **Rationale**

Participants report PEx as a key health information resource important to their health decision making (France et al., 2011). However, participants are apprehensive to introduce online sourced health information into appointments with their HCP (as discussed in Chapter 2), despite HCPs encouraging such information integration (Chapter 5). In light of these findings, the current study employed an experimental design to investigate whether PEx information presented on a website, accompanied by either a self-reflection prompt or a discussion starter prompt, can increase intentions to discuss online health information with an HPC and can increase decision satisfaction.

Although it would be preferable to observe the performed behaviour of patients searching for and integrating PEx information into HCP appointments in real-time in a naturalistic setting, time constraints applied to this project timeframe mean that longitudinal research methodologies are not feasible. A number of experimental methodologies however have been utilised in previous research exploring the role of PEx information within the context of health related decision making. For example, eye tracking technology has identified message formats (text versus video) to differentially influence information search behaviours in a web-decision aid (Shaffer, Owens, et al., 2013), and a randomised control trial found patient decision aids comprising patient narratives significantly reduced postoperative decision conflict (Osaka & Nakayama, 2017). Hypothetical decision making tasks are a popular method used to investigate the influence of PEx information on intentions and health decision making (De Wit et al., 2008; Ubel et al., 2001), and are discussed in Chapter 2 (Literature Review). Hypothetical decision making tasks pertinent to the present study identify that patient narratives existing in social media significantly

influence treatment recommendations (Caro et al., 2014) and confidence to make a decision (Shaffer, Hulsey, et al., 2013). For example, in order to explore the effects of patient narratives on breast cancer treatment decisions, Shaffer, Hulsey, et al. (2013) developed video patient narratives for their hypothetical treatment decision task. Participants were asked to imagine that they had been diagnosed with early stage breast cancer and to choose between a mastectomy and lumpectomy with radiation. Participants were randomly assigned to one of four experimental conditions, where each represented a different manipulation of the patient narratives' emotional valence (positive versus negative) and content (process versus experience focussed discussion). The authors found that process narratives encouraged information search, and experience narratives improved evaluations of the decision process. Participants in the experience condition also reported greater immersion the narrative story. In another hypothetical breast cancer decision making task, Shaffer, Owens et al. (2013) used text versions of the patient video narratives. The success of Shaffer et al's breast cancer hypothetical treatment decision tasks to assess the effectiveness of message formats (text versus video) and information manipulations (process versus experience) informed the present study methodology. The rationale for using breast cancer as the chosen health topic is twofold. Firstly, Shaffer, Hulsey et al. (2013) conclude that choosing a breast cancer treatment option raises additional health decisions (such as postoperative appearance), thus reflects the nature of health decisions. Second, materials produced for Shaffer et al's research were developed from real patient stories from published decision aids, and are ready available (upon request from the authors). This ensures that the patient stories utilised in this studies represent and detail real stories, and reflect real examples of the process and experiences of choosing a breast cancer treatment decision. To conclude, PEx information is an important health information resource (Chapters 3-4), specifically, self-reflection processes help health consumers reflect upon, and evaluate PEx information to inform subsequent health related decisions (Sillence et al., 2014). Findings reported from this thesis (Chapters 1-4) and in the literature highlight that whilst PEx is used to inform patients health decisions, a number of barriers prevent patients introducing and sharing the information with HCPs. In Chapter 5, HCPs encouraged and discussed how patients can discuss online health information in appointments. Such encouragement from the HCP is shown to facilitate the integration of online sourced health information into appointments (Entwistle, Prior, Skea, & Francis, 2008). Given the benefits associated with patients contributing ideas and information into discussions with HCP, the present study employed a hypothetical decision making task to investigate whether PEx

information accompanied with either a self-reflection prompt and/or a discussion starter prompt, can increase intentions to introduce PEx information into conversations with HCPs, and affect decision satisfaction. It is expected that intentions to discuss PEx information with HCPs, and decision satisfaction, will be greatest when PEx information is presented with self-reflection and/or a discussion starter prompt.

## **7.2 Method**

### **7.2.1 Design**

Informed by the methodology of Shaffer, Hulsey et al (2013) and Shaffer, Owens et al. (2013), the present study employed a hypothetical breast cancer decision making task which required participants to imagine themselves in a health related scenario, and make a treatment choice after reading patient narratives which described the decision making experience and process.

This study employed a 2 (self-reflection absent or present) x 2 (discussion absent or present) independent groups factorial design. Participants were randomly allocated to one of four conditions. The dependent variable was the participant's intentions to discuss the PEx information.

### **7.2.2 Participants and recruitment**

Through purposeful sampling, 140 women from the United Kingdom responded to poster and email advertisements distributed across Northumbria University campus, to take part in a computer-administered hypothetical breast cancer decision making task. Participants were required to be 18 or older, and have no previous diagnosis of breast cancer. Participants were predominantly Caucasian (82.1%), with a mean age of 26.74 years ( $SD = 9.40$ ), age range = 18-56.

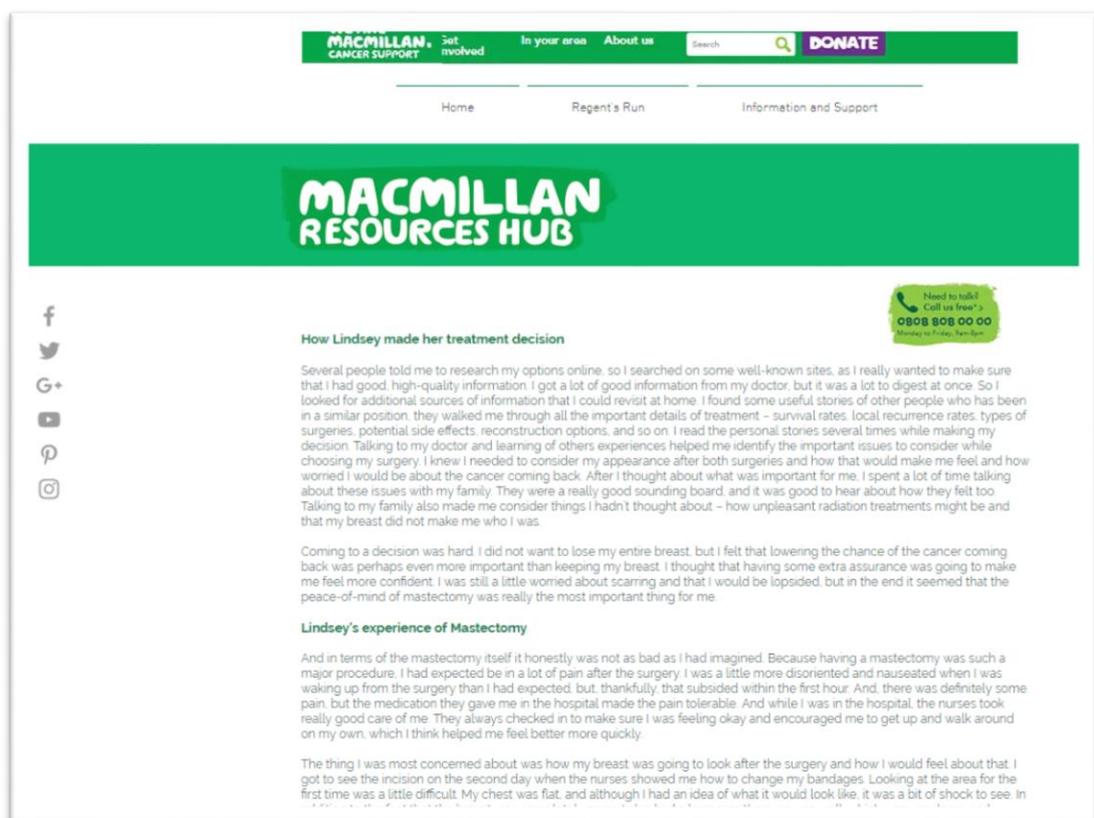
### **7.2.3 Procedure and materials**

This study was granted ethical approval from Northumbria University's Faculty of Health and Life Sciences Ethical Committee.

Participants were able to participate in this study through a face-to-face testing session or via email instruction. Upon opening the online study link, participants were asked to imagine themselves in a health scenario (appendix 9.17). This scenario informed the participant of their recent breast cancer diagnosis, and that they were required to make a treatment choice between a Mastectomy and Lumpectomy with Radiation therapy. The scenario detailed how the cancer was diagnosed, defined key terms such as biopsy,

lumpectomy, and mastectomy, and highlighted important factors to consider when making a decision. The task scenario and patient narratives were provided by Shaffer, Hulsey, et al. (2013) (with permission), who developed the materials for their hypothetical breast cancer decision making study. To ensure the materials were relevant to this UK sample, the researcher reviewed the narratives multiple times and adapted American terminology to British.

To help them with their decision, participants then read four patient stories written by real breast cancer survivors, who described their experiences with breast cancer diagnosis, the process of making a treatment decision, and living with the outcomes (for an example, see appendix 9.18). These narratives were presented on a health website (see Figure 7.1), created by the researcher that was modelled on a respected cancer support website (www.cancerresearchuk.org). For a side-by-side comparison of these websites, refer to appendix 9.19.



**Figure 7.1.** Depiction of PEx information presented on a website

Participants read the same experiences, however, participants allocated to the self-reflection condition, or discussion starter condition also saw information presented in

Figure 7.2 (the self-reflection component is shown on the left, discussion starter prompt is shown on the right).



**Figure 7.2.** Self-reflection and discussion starter prompts

After reading the patient narratives, participants were asked to complete the study survey to indicate their chosen treatment, evaluate their decision, report their intentions to integrate the information into discussions with their healthcare professionals and provided demographic information (see appendix 9.20 for survey questions). Participants also completed a measure of task engagement to ensure that any findings were not due to differences in engagement. Though the current study was not concerned with the actual choice of treatment made, it was important to include a treatment choice task for participants in order to maintain the face validity of the task. Participants took approximately 30 minutes to complete the task, and were compensated a £5 voucher and debriefed upon completion.

### Survey Measures

The survey items chosen for this study were taken from validated scales and previous literature as discussed below.

*Treatment Decision.* Based on previous research (Shaffer, Hulsey, et al., 2013), participants were asked to report their treatment decision using a single item (“Please indicate your treatment decision”) on a scale from 1= *extremely likely to choose lumpectomy with radiation*, to 7 = *extremely likely to choose mastectomy*.

*Decision Satisfaction.* Based on previous research (Shaffer, Hulsey, et al., 2013), participants completed nine items assessing decision satisfaction. These items included: “I am confident in my ability to make an informed choice”, “I thoroughly considered all of the relevant factors”, “I am prepared to make this treatment decision”, “I have a good understanding of the information presented”. All items were rated on a seven-point Likert scale (1= *strongly disagree*, 7 = *strongly agree*,  $\alpha=.86$ ). PCA/reliability analysis identified

item 6 insufficiently correlated with the overall scale and was subsequently removed from the analysis. The final scale contains 9 items ( $\alpha=.89$ ).

*Intentions to discuss online health information with Healthcare Professional.* To investigate whether the different conditions would affect information integration, participants responded to 5 questions developed by the researcher. These included: “I feel comfortable in discussing the information with my healthcare professional”, “I feel confident discussing the information with my healthcare professional”, “I feel comfortable summarising the information with my healthcare professional”, “I feel better able to ask my healthcare professional questions” on a Likert scale (1= *strongly disagree*, 7 = *strongly agree*;  $\alpha= .89$ ).

*Task Engagement.* Based on previous research (Busselle & Bilandzic, 2009), participants responded to 9 questions to measure participants engagement with the narrative information. These included: “At points, I had a hard time making sense of what was going on in the stories”, “My understanding of the characters is unclear”, “While reading the stories I found myself thinking about other things”, “I felt like I could empathise with the characters in the stories” (1= *strongly disagree*, 7 = *strongly agree*;  $\alpha= .71$ ).

## **7.3 Results**

### **7.3.1 Task engagement**

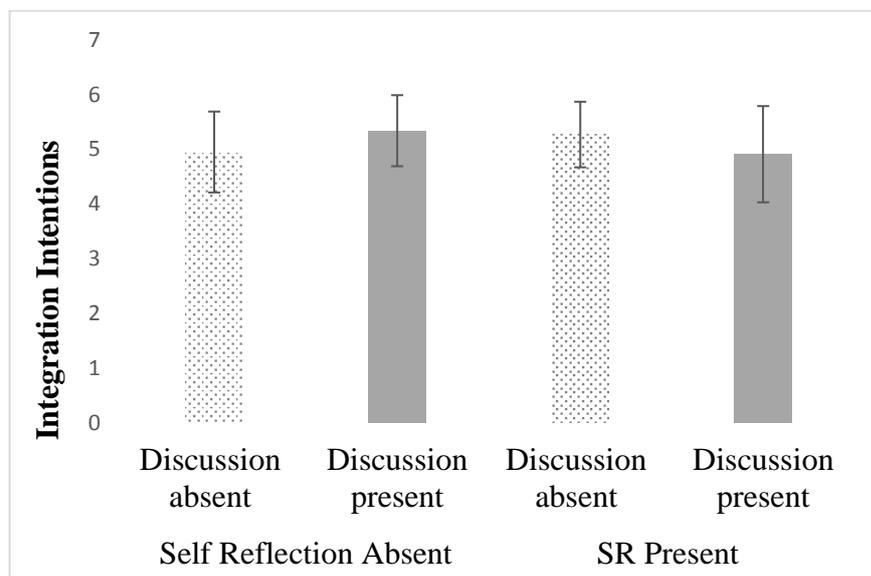
Task engagement scores did not differ between the experimental conditions which suggests that study findings were not attributable to differences in participant’s task engagement.

Mean engagement scores ( $M= 4.76$ ,  $SD= 0.57$ ) were significantly higher than the normal score of 4,  $t(139) = 98.768$ ,  $p < .001$ . There was no significant main effect of the presence ( $M= 4.75$ ,  $SD= 0.55$ ) or absence ( $M= 4.77$ ,  $SD= 0.59$ ) of self-reflection condition on task engagement scores,  $F(1, 136)= .039$ ,  $p = .844$ ,  $\eta_p^2 < .01$ . There was no significant main effect of the presence ( $M= 4.76$ ,  $SD= 0.63$ ) or absence ( $M= 4.75$ ,  $SD= 0.51$ ) of the discussion starter condition on task engagement scores,  $F(1, 136)= .038$ ,  $p = .847$ ,  $\eta_p^2 < .01$ . There was also no significant interaction effect between condition and task engagement scores  $F(1, 136)= <.01$ ,  $p = .998$ ,  $\eta_p^2 < .01$ .

### 7.3.2 Intention to discuss online health information with healthcare professional

There was not a significant difference in integration when self-reflection was present ( $M=5.09$ ,  $SD=0.77$ ) compared to when it was absent ( $M=5.15$ ,  $SD=0.72$ ),  $F(1, 136)=0.22$ ,  $p=.643$ ,  $\eta_p^2=.002$ .

There was no significant main effect of the discussion condition ( $M=5.13$ ,  $SD=0.80$ ) on integration scores,  $F(1, 136)=.019$ ,  $p=.889$ ,  $\eta_p^2<.01$ . There was also no significant differences between the discussion condition and the no discussion condition ( $M=5.11$ ,  $SD=0.70$ ). There was a significant interaction between the self-reflection condition and the discussion condition,  $F(1, 136)=9.422$ ,  $p=.003$ ,  $\eta_p^2=.065$ . The pattern is reflected in Figure 7.3. The figure shows that integration intentions were higher when discussion is present in the absence of self-reflection, than when discussion is absent and self-reflection is present. Also, the figure shows that integration was higher when self-reflection is present in the absence of discussion, than when both discussion and self-reflection are present. Rerunning the analyses controlling for treatment choice did not make any difference to the findings.



**Figure 7.3.** Mean integration intentions when self-reflection and discussion components are present and absent.

A simple effects analysis showed that when self-reflection is present, people have higher integration intentions in the absence of discussion ( $M=5.27$ ,  $SD=0.60$ ) than in the presence ( $M=4.91$ ,  $SD=0.88$ ) of discussion ( $p=.040$ ). By contrast, when there is no self-reflection, people have higher integration intentions in the presence of discussion ( $M=5.34$ ,  $SD=0.65$ ) than the absence of discussion ( $M=4.95$ ,  $SD=0.74$ ) ( $p=.025$ ). Overall,

this finding means that integration intentions are higher in the presence of self-reflection or discussion, but not when they are both present.

### **7.3.3 Decision satisfaction**

There was no significant main effect of the presence ( $M= 4.61, SD= 0.65$ ) or absence ( $M= 4.46, SD= 0.82$ ) of self-reflection condition on decision satisfaction scores,  $F(1, 136)= 1.406, p = .238, \eta_p^2 = .010$ . There was no significant main effect of the presence ( $M= 4.59, SD = 0.66$ ) or absence ( $M= 4.48, SD= 0.81$ ) of discussion starter condition on decision satisfaction scores,  $F(1,136)= .810, p = .370, \eta_p^2 = .006$ . There was no significant interaction effects for the conditions on decision satisfaction,  $F(1,136)= .972, p = .326, \eta_p^2 = .007$ . The analysis was rerun to control for treatment choice and made no difference to these findings.

## **7.4 Discussion**

The present study aimed to investigate whether PEx information accompanied by either a self-reflection prompt and/or a discussion starter prompt, can increase intentions to introduce PEx information into conversations with HPCs, and affect decision satisfaction.

Although there were no significant main effects of experimental conditions on integration intentions, there was a significant interaction effect. This showed that when self-reflection is absent and discussion is present (and vice versa) participants' intentions to integrate online health information into interactions with their HCP, are higher than when self-reflection and discussion are both present. These findings suggest that the components under investigation (self-reflection and discussion starter) when paired with health narratives, can be utilised to benefit the communication between patients and HCPs, as findings show a significant positive impact on integration intentions. However, the presence of both components (self-reflection and discussion starter) simultaneously did not contribute to higher integration intentions. Previous research notes that reading requires more cognitive effort than watching a video (Wilson & Wolf, 2009), and so video narratives are reported to be more persuasive (Shen, Sheer, & Li, 2015) and encourage greater information search (Wilson & Wolf, 2009) than messages in text format. Therefore, it is possible that the inclusion of both components which were also in text format, may have overwhelmed the participants. Overloading participants with text based information in this way is likely to have increased the cognitive effort required to

complete the task (Herbig & Kramer, 1994), potentially causing the effects of one component to negate the usefulness of the other.

It is also possible that the nature of the self-reflection component encouraged participants to ask themselves more questions after reading the narratives, potentially motivating participants to want to conduct their own information search to appease any queries. Prior research has found that showing participants patient narratives increases subsequent information search (Shaffer, Hulsey, et al., 2013; Shaffer, Owens, et al., 2013). Therefore, if the self-reflection component motivated participants to conduct their own information search, the second component (discussion starter) may not have been appropriate or useful at this time.

The significant interaction demonstrates that this study was successful in its attempt to affect intentions to integrate online sourced health information with healthcare professionals, by experimentally manipulating components accompanying PEx information on health websites. These findings compare favourably with those of Silver (2015) who found advertisements that encouraged patients to talk to a doctor facilitated communication, and those reported by Fox, Harris, and Jessop (2017), who identified narratives paired with self-affirmations promoted behaviour change. The present study contributes to the literature, and furthers Fox' findings, by identifying that too many additional components attempting to nudge behaviour do not boast additive effects, but work optimally when presented singularly. Thus, these findings show preliminary support for bridging the gap between online health information seeking and disclosing online health information searching with health professionals.

The findings revealed no differences in decision satisfaction scores across conditions, and are consistent with those reported by Shaffer, Hulsey, et al. (2013). It is possible that the present study design did not permit the emergence of any differences. While the four conditions each contained PEx information, the inclusion of a static information condition, conveying statistical and risk information, may have permitted the emergence of differences in decision satisfaction scores across the experimental conditions. Given what we know from Chapter 6, it is conceivable that inclusion of this additional condition would show greater decision satisfaction scores for participants in the PEx conditions than those in the static condition. Alternatively, it may have been more appropriate to adapt the decision satisfaction questions to capture the usefulness of the self-reflection and discussion components, e.g. "the self-reflection exercise helped me to think of my own situation", as the current decision satisfaction questions reflect satisfaction with the

decision rather than satisfaction with the self-reflection and the discussion starter prompts to contribute to the decision to integrate PEx information with the HCP.

We also know from the literature that perceived website trust is associated with decision making and satisfaction (Harris et al., 2011). In this study, the information was presented to all participants on a website designed to mimic a distinguished and trusted charity website. It is conceivable that if the information were presented on a website containing features which participants deem to be untrustworthy such as advertisements or promoting or selling a product or service (Sillence et al., 2014), this would have affected participant ratings of decision satisfaction. Future studies should consider manipulating the information source in order to examine the role of information trust on decision making and decision satisfaction in experimental research designs. Doing so would be more representative of the types of websites often used in health information searching and health decision making.

The present study findings show high scores for decision satisfaction irrespective of condition. These findings are in line with previous literature that shows narratives to positively impact decision evaluation (Shaffer, Hulsey, et al., 2013). However, it is worth noting that the effects of narratives are connected to its content (outcome, process and experience of decisions), purpose (e.g. to provide information or to make healthcare materials more engaging) and evaluative valence (negative or positive) (Shaffer & Zikmund-Fisher, 2012). As the present study did not manipulate these dimensions, it is unknown whether ratings of decision evaluation were influenced by any of these aspects and it would be interesting for future research to examine these components individually to investigate how each component affects decision evaluation.

Regardless of experimental condition, the results show that participants did not differ in their task engagement scores. Thus is perhaps unsurprising given that the narrative content was consistent across conditions (participants saw the same narratives). The engagement measure should be considered a strength of this methodology. It was important for the present study to ensure that any findings were not due to differing levels of engagement across conditions, or participant disengagement with the task, this is particularly important given the use of a volunteering sample, who may have been motivated to take part in the study for monetary compensation. The consistent scores across conditions suggest that the task was engaging despite requiring cognitive effort. Participants described enjoying the task, commenting on how emotionally evoking the

patient stores were, encouraging them to reflect on what decision they would make if it was their reality.

#### **7.4.1 Conclusion**

This novel study employed a hypothetical decision making task in order to investigate the potential to encourage integration of PEx information with a health professional. The findings contribute to knowledge and add to those reported by Shaffer et al, by demonstrating the usefulness of their breast cancer decision-making task and materials, as a vehicle to explore a related topic – intentions to discuss online health information with a health professional. Chapters 3-5 highlighted incongruent views between patients and health professionals, regarding the use and integration of online health information (patient narratives in particular) to support health decision making. The present study findings provide preliminary evidence in support of positively influencing patient intentions to integrate PEx information into discussions with healthcare professionals. This study can have far reaching implications for the use of digital health information to inform and support health decisions. The development of a plain language patient deliverable, detailing ways to search and appraise health websites and information, including self-reflection and advice regarding how to integrate the information into discussions with HCPs, is an easy low cost way to encourage effective, safe, health information searching to support patients' health decisions.

#### **7.4.2 Strengths and limitations**

The present study employed a relatively youthful sample with a mean age of 27 years, in comparison to the sample in Shaffer, Hulse, et al. (2013) (mean age = 51 years). Though participants in the present study may not consider the topic of breast cancer as relevant to their age, participants engaged with the patient stories and the findings suggest this sample are likely to integrate online sourced PEx information into healthcare appointments. Given that the NHS offer breast cancer screening to women in the UK from the age of 50 (NHS, 2018), it would be useful to replicate the study with a participant sample age closer to the breast cancer screening age, in order to investigate intentions to integrate PEx information. Research indicates that narratives are more persuasive on female participants (Shen et al., 2015), but future research should be extended to a male sample to investigate the influence of patient narratives (in particular the influence of emotional messages and emotional engagement) and intentions to discuss information with health professionals.

The introduction of this chapter provides a rationale for the use of a hypothetical decision making task in this study, and this thesis provides evidence in favour of, and emphasises the importance of viewing health decision making from a DDM perspective. The nature of the hypothetical decision making task in this study does not reflect the real timeframe between condition diagnosis and choosing a treatment decision in real life, nor can it capture the emotions, use of technologies, and discussions with friends and family, as described by the notion of DDM. Therefore it is important to acknowledge that the task may have been difficult for participants to envisage and immerse themselves in (Halpern & Arnold, 2008; Ubel et al., 2005; Wilson & Gilbert, 2005). Future studies should aim to conduct longitudinal research following individuals from the point of diagnosis, to investigate ways in which we can encourage discussion of online health information with health professionals. This would also assist in investigating whether intentions to integrate online health information (as identified in this study) are carried out, given that there is ample evidence for the existence of an intention-behaviour gap (Webb & Sheeran, 2006). To summarise, these findings should be interpreted as an early indication suggesting we can influence intentions to discuss online information with an HCP.

## **7.5 Chapter summary**

This chapter described an experimental manipulation of information accompanying PEx information on a health website. This study sought to investigate whether self-reflection and/or discussion starter accompanying patient narratives could affect intentions to discuss the information with healthcare professionals. This was because Chapters 3-5 identified the need for transparency from patients when incorporating their health knowledge and information seeking into discussions with a HCP. This study used a hypothetical decision making task as it was considered the most appropriate method to investigate the aims, and has been used throughout previous research with regards to the use of patient narratives for health decision making. It was found that the presence of self-reflection and discussion information alone, not in tandem, significantly and positively affected participant intentions to discuss the online patient narratives with their HCP. The findings also showed no differences between experimental conditions on levels of task engagement and decision satisfaction.

The final chapter moves onto a general discussion of the PhD work. It provides a summary and discussion of each of the five studies and clearly describes how each of the PhD research aims and objectives were met. It also considers overall strengths and limitations of the PhD, future research and implications of the PhD findings.

## **Chapter 8: General Discussion**

This discussion considers the findings from the five research chapters reported in this thesis, and highlights how each study contributes to knowledge by answering the research questions. This chapter is divided into 6 sections. The first section provides an overview of the thesis aims and research questions. The second and third sections reflect on the five research studies in relation to the literature in Chapter 2, and considers how the work presented in this thesis has contributed to existing knowledge. The implications of these findings are provided in section four. Sections five and six comprise an overview of the limitations of this research and future research suggestions.

### **8.1 Research aims**

The aim of this thesis was to examine the ways in which internet resources support health decision making across a range of health decisions and issues, and to improve patients' integration of online health information into healthcare appointments. This involved working with both individuals who have used the internet to support a health decision regarding a long term or short term health complaint, and health professionals. This enabled all perspectives to be considered when thinking how to encourage and increase patients' integration of internet sourced health information into medical consultations with HCPs.

This thesis employed a mixed methods approach across five studies to explore two research questions:

- 1) Examine the ways in which internet resources support health decision making across a range of health conditions and issues
- 2) Improve and encourage the integration of online health information into interactions with HCPs

#### **8.1.1 Research objectives**

As discussed in the Introduction (Chapter 1) the thesis had five specific research objectives in order to answer the two research questions. These research objectives were explored both with HCPs (Chapter 5), and individuals who have used the internet to inform long term and short term health related decisions (Chapters 3,4,6,7). The research objectives were to:

- Identify the role of the internet in supporting health decision making in individuals with long term health conditions (Study 1)

- Examine how individuals with short term health complaints use online health information to inform health decisions (Study 2)
- Identify health professionals' views of the internet informed patient, and the influences on the professional-patient relationship, and consultation experience (Study 3)
- Quantitatively examine how online health information is used in health decisions, exploring the role of trust and empowerment in decision satisfaction (Study 4)
- Develop an intervention that can increase patient intentions to integrate online health information with their healthcare professional (Study 5)

The first research question was explored by building on previous research that primarily focussed on how individuals with chronic health conditions used the internet to support treatment decisions. Literature discussed in Chapter 2 (Literature Review) highlighted that health decisions are not restricted to one off treatment decisions made in the presence of a health professional within the confines of a medical appointment. Rather, that multiple health decision making activities exist (Entwistle & Watt, 2006) and that decisions can be formed, informed, and transformed over time, and through discussions with family, friends, ancillary health professionals and engagement with technologies (Rapley, 2008). This research is pertinent as the contemporary emphasis for patients to engage and collaborate within their healthcare (The Department of Health, 2012), means that more patients are sourcing advice and information from the internet to assist with their health decisions. Whilst previous literature has examined extensively the impact of online health information on treatment choices for individuals with chronic conditions, research has seldom investigated the impact of online health information on other health related decisions, and has not considered how individuals with short term health complaints use the internet to support their health decisions. Therefore, this research aimed to investigate how individuals with long term and short term health conditions use online health information to support their health related decisions.

The second research question was concerned with improving the integration of online health information into medical appointments with healthcare professionals. The literature suggests that patients believe that healthcare professionals do not want them to contribute their own information to appointments (Ahmad et al., 2006; Caiata-Zufferey & Schulz, 2012). However, recent findings show HCPs hold perspectives that are more positive regarding internet informed patients. Whilst this shift in views is reported throughout psychological literature see (Macdonald et al., 2018; Van Riel et al., 2017) it

seems that patients are unaware of this change in thinking. Disclosing and discussing online health information with health professionals is beneficial to the consultation, therapeutic relationship, patient health outcomes and patient satisfaction (Bylund et al., 2007; Street et al., 2009), therefore, it is important to encourage patients to integrate their online health information searching into the medical appointment. Building on existing research around the design of health information, this research question was to improve intentions to integrate online health information into appointments.

A summary of how the two research questions were addressed through five studies presented in this thesis, and how the five research objectives were incorporated into the studies is discussed in sections 8.2 and 8.3 below.

## **8.2 How does the internet support health decision making across a range of health conditions and issues?**

The first research question aimed to understand how the internet supports health decision making across a range of health conditions. This was investigated by three research studies, two were qualitative and one quantitative. A summary of each of the studies is presented below, followed by a discussion of the combined implications.

Study 1 was a qualitative study that aimed to explore how individuals with long term health conditions used the internet to support their health decision making, from a DDM perspective. Previous research has seldom viewed health decision making from a broader perspective and has primarily considered the role of online health information in treatment choice in individuals with chronic, long term health conditions. Semi-structured interviews were analysed using thematic analysis and data presented around two key themes (1) *Empowering processes* (2) *Integrated decision making*. Within the first theme, participants described interacting and conversing with multiple online information resources, which contributed new knowledge regarding various decisions that needed to be made, of which participants were previously unaware. Participants also described how communicating and reading others' experiences online created a sense of social support that encouraged and supported their decision making. In the second theme, participants discussed using online health information to assist with a number of health decisions concerning medical treatments, requesting emergency intervention, and product purchases. These decision activities indicated the ways in which online health information assisted with supporting and initiating different decisions over time and away from the consulting room. When online health information led participants to seek health

professional intervention, participants used the internet to prepare for the appointment, in order to support discussions with the professional, and consider in advance the possible outcomes that the professional might propose. These findings emphasise the need to consider health decisions in a broader sense, as participants highlighted using the internet to inform many different kinds of decisions above and beyond simply treatment choice.

Study 2 also employed a qualitative approach to investigate how individuals with short term health complaints use the internet to support their distributed health related decision making. Professional and organisational bodies encourage the participation and involvement of patients in their healthcare. However, like most of these campaigns, research focuses on how individuals with chronic health conditions use the internet to support and manage their health decisions, possibly because condition management can prevent the emergence of further problems and reduce healthcare costs. Thus, it was important for this study to consider how individuals with short term health complaints use the internet to support health decisions, to address the gap in literature. Thematic analysis of semi-structured interviews identified three key themes (1) *The internet as a triage device*, (2) *Going solo: Making the decision alone*, (3) *Information negotiation and integration*. In the first theme, participants described primarily using the internet to help decide whether or not seek professional intervention. Conversely, the second theme described how participants used the internet to inform health decisions that did not require professional intervention, and which took place in the participants' own environment. In the third theme, participants discussed sourcing online health information to support their efforts to integrate the information into healthcare appointments, specifically, learning the medical terminology enabled participants to converse more eloquently with the HCP and contribute to decisions. The findings of this study suggested that individuals with short term health complaints used the internet differently for health related decisions than individuals with long term health conditions in study 1, whilst providing further evidence in support for the integrated nature of decision making also identified in study 1.

Study 4 explored findings from Study 1 and Study 2 quantitatively in a large scale online survey. The survey questions were informed by the findings of empowerment and information integration in Study 1 and Study 2 and addressed how participants' perceptions of website and information trust also contributed to decision satisfaction. The online survey was administered to 196 participants who had used the internet to inform a health decision regarding a long term or short term health complaint. Analyses showed a significant association between health complaint length (long term versus short term) on

visits to a health professional, the types of decision being made, and the type of information consulted. Respondents reported different motivations who reported seeing a health professional after their online health searching reported different motivations for this decision and those respondents who did not see a health professional reported being able to make the decision alone. Lastly, analyses showed that viewing PEx information, and perceived trust, indirectly predicted participants' decision satisfaction. Overall, the findings confirm those in Study 1 and Study 2 regarding the differential use of the internet as a decision support tool, and contribute novel findings regarding the pathways through which online health information seekers achieve decision satisfaction.

This thesis has contributed to previous literature by identifying how individuals with long term and short term health complaints use the internet as a decision support tool. Previous literature has heavily focused on how individuals with chronic conditions use the internet to support treatment choice (as discussed in Chapter 4). This thesis considered Rapley's (2008) notion of distributed decision making throughout, and findings from qualitative and quantitative studies show that the internet is used to support a multitude of health decisions, occurring within and outside of medical environments. The findings demonstrate the integrated nature of health decisions, and encourage future work to consider health decisions from a broader perspective, in order to gain a more comprehensive understanding regarding the broader role of the internet as a decision support tool. This thesis employed a mixed methods approach, using quantitative methods to follow up and expand findings from initial qualitative studies. The qualitative findings in this thesis were thus strengthened by the use of a large-scale survey.

Empowerment processes identified qualitatively in Study 1 and Study 2, highlighted that participants with long term and short term health complaints feel more informed, knowledgeable, and supported in their health decision making by engaging with online health information, specifically, information provided by people with similar health issues. These findings were confirmed quantitatively in Study 4 with a larger and more varied sample, but specifically identified the role of positive affective empowerment (described as positive feelings/thoughts about making a decision). The findings are consistent with previous research that identifies similar empowering processes and outcomes in OSGs for specific health conditions such as HIV, ADHD, fibromyalgia, arthritis and breast cancer (Mo & Coulson, 2014; van Berkel et al., 2015; van Uden-Kraan, Drossaert, Taal, Shaw, et al., 2008), such as exchanging information, sharing experiences, and encountering emotional support. However, findings pertaining to the

predictive role of positive affective empowerment are novel to this thesis. Study 4 identified that positive affective empowerment mediated the relationship between participants' trust in online health websites and information and decision satisfaction, and mediated the pathway between PEx information and decision satisfaction. It thus seems that emotional aspects of empowerment play a key role in how online health information seekers become satisfied with their decision. These findings lend support to research that identifies that negative messages can trigger negative emotional responses that influence message processing and judgements (Skalski et al., 2009), and that message framing can encourage protective health behaviours such as mammography screening, smoking cessation and reduced alcohol consumption (Bernstein et al., 2015; Schneider et al., 2001; Steward et al., 2003). Therefore, it is conceivable that engaging with PEx information and attributing trust to information, influences consumers sense of agency which empowers them to become satisfied with their decisions, possibly, as decisions were informed by information which they consider trustworthy and from credible sources (i.e. similar others in PEx information).

Study 1 and Study 2 showed that patients consult the internet to inform their knowledge and understanding regarding their health complaint but are apprehensive to disclose their online searching or their findings to their HCP. Barriers to the integration of online health information into the appointment identified in this thesis are consistent with those in published literature, such as embarrassment, not knowing how to integrate the information, and fear of the professional reaction (Joseph-Williams et al., 2014; Silver, 2015; Tan & Goonawardene, 2017).

In summary, in Study 1 and Study 2, participants with long term and short term health complaints reported using the internet to gain knowledge and prepare for an appointment with a HCP; however, many expressed their apprehension to introduce the topic of their internet searching through fearing the HCPs response, and not knowing how to bring up their information searching. These findings were also confirmed in the larger scale quantitative survey in Study 4, which in addition presented novel findings that identified affective empowerment mediated the relationship between participants' use of PEx information, and perceived website and information trust, and decision satisfaction. It was concluded that patients' intentions to integrate online health information into healthcare appointments and discussions with their HPC, need to be encouraged in order to facilitate and participate in collaborative decision making with the HCP, and to foster responsibility in health decisions. Taken together, PEx information, trust, and the participants need for

encouragement were taken forward to the next studies that investigated whether participants' intentions to discuss online health information could be increased through different manipulations of health information on a website.

### **8.3 Can intentions to integrate online health information into interactions with healthcare professionals be improved?**

The second research question aimed to investigate whether intentions to discuss online health information with HCPs can be increased. Two research studies investigated this question qualitatively (Study 3) and quantitatively (Study 5). A summary of each of the studies is presented below, and implications of the findings are then discussed in section 8.4.

Study 3 employed a qualitative methodology to explore HCPs views and perspectives on the internet informed patient, and the effects on the therapeutic relationship and consultation. This research aimed to gain a different stakeholder perspective regarding patients use of internet to inform health decisions. Ten HCPs with various roles within healthcare responded to five scenarios that were adapted from participant interviews in Study 1 and Study 2. The scenarios described the experience of 5 patients, who each used the internet in a different way to inform health decisions. Interviews were analysed using thematic analysis and data presented around two key themes (1) *Being transparent and honest* (2) *Improving integration*. The first theme centred on professionals positive reactions to internet informed patients, and encouragement for patients to be open and honest about their online health information searching. The second theme described the benefits of patients discussing their online information searching and offered recommendations regarding how patients can introduce this information into the appointment. Overall, HCPs encouraged the integration of internet information during appointments. This highlights discordance between patients' understandings of HCPs views on internet informed patient, and HCPs actual views. HCPs recommendations regarding how patients can introduce online information into the appointment, suggests that patients require encouragement in order to increase integration intentions.

Study 5 employed a quantitative, experimental design that aimed to increase intentions to discuss information with a HCP. This study aimed to test the effectiveness of self-reflection prompts and/or discussion starter prompts accompanying PEx information to increase participants' integration intentions. One hundred and forty women read PEx information presented on a health website, and responded to questions measuring their

likelihood to integrate the information into discussions with an HCP and their decision satisfaction. Findings showed a significant interaction between the self-reflection and discussion starter components, this meant that intentions to integrate PEx information into discussions with health professionals was higher when PEx was accompanied with either the self-reflection component or the discussion starter component, than when both were presented together. These findings suggested that patient intentions to discuss online health information with HCPs can be increased with single information prompts.

The findings suggest that both the self-reflection and discussion starter components were effective at increasing participants intentions to bring online health (PEx) information into discussions with an HCP. The self-reflection component was informed by the 'engagement loop' phase in Sillence et al's (2014) model of engagement in peer to peer healthcare, the success of this component to affect participant intentions confirms use of this phase when consumers consider PEx health information. Similarly, success of the discussion starter component corroborates findings from Study 3, which suggested that encouragement to integrate and discuss online health information could facilitate this integration. However, the findings also fit with those by Herbig and Kramer (1994), in that information overload may not have the desired additive effect. It is important to consider that the PEx information was presented on a website designed to mimic a well-known and trusted health website. Given that superficial features of websites inform information credibility judgements (Sillence et al., 2013), participants' intentions to integrate the information may have been affected by the platform or the website characteristics. Success of the self-reflection and discussion starter component should be tested on other websites where health information is sourced, to investigate further the influence of these two components on integration intentions.

## **8.4 Implications of findings**

As discussed earlier in this thesis, the use of online health information to support health related decision making has increased (Blank & Dutton, 2013). This behaviour is in line with current governmental guidelines that encourage patient participation in healthcare (The Department of Health, 2012). In response to the increase in internet informed patients, psychological research has largely considered how online health information (both factual and PEx) can contribute to and affect patients' treatment decisions. However, this narrow focus does not capture the complexity in decision making, as exemplified in Rapley's notion of DDM (Rapley, 2008), and Entwistle and Watt's (2006) stages of decision making activity.

The current emphasis on patient involvement in healthcare advocated by The Department of Health and the NHS, centres on patient engagement and shared decision making with an HCP usually within the confines of the traditional dyadic medical appointment. However, findings presented in this thesis substantiate Rapley's (2008) call for a more distributed perspective on healthcare, as results demonstrate health decisions extend beyond the confines of a medical appointment, and are informed and transformed through interactions with multiple knowledge sources (friends, family, and the internet) over time. Importantly, although the vast majority of literature considers the impact of the internet on important treatment decisions made in tandem with HCP guidance, findings in Chapter 4 showed that the internet was also used to initiate and sustain decisions away from the HCP. While many of these decisions were straightforward, some were potentially dangerous, such as adapting medication dosages, and purchasing treatment related products via the internet without HCP advice or intervention. These particular findings highlight the importance for government bodies and other advocates of patient engagement in healthcare, to consider how the internet is used to inform a range of health decisions, and to maximise efforts to consider how best to include multiple stakeholders, including HCPs in potentially serious decision making.

Despite encouragement from governmental bodies such as The Department of Health and the NHS for patients to participate in shared decision making with a HCP, Chapters 3-6 identified tensions between patients' understandings of HCP's views on internet informed patients, and HCP's actual views. Specifically, Chapter 6 identified factors that prevented patients from taking online sourced health information to the HCP. Patients reported feeling embarrassed and unsure as to how to integrate the information into appointments. Chapter 7 identified that encouraging patients to appraise online health information and to reflect on its personal relevance was a useful way of increasing intentions to discuss online resources with the HCP. Likewise, providing cues as to how to discuss this information with the HCP was also seen as beneficial. Thus, these findings provides preliminary evidence about bridging the gap between online health information and face to face consultations.

Implications from this thesis apply to both patients and HCPs. Firstly, findings identified that self-reflection and discussion starter components can be used to accompany online health information in order to affect participants' intentions to take the information forward to a HCP. Thus, this thesis shows preliminary evidence that an intervention embedded within health websites targeting consumer's online behaviours and intentions,

can work to improve and encourage integration of online health information into appointments. Although these findings are preliminary, the intervention is a cost effective, simple method to target consumers' online health behaviours, and could be used to accompany health information presented on a range of health websites

Although this intervention increased intentions to seek an appointment with a HPC, it is important to remember that participants in Chapters 3-4 reported that negative HCP reactions can discourage integration of information in appointment, and in some cases damage the patient-professional relationship. Therefore, it is also important to recognise that HCPs are also responsible for ensuring that patients feel safe and secure discussing online health information with them. Discussions with HCPs in Chapter 5 informed the 'discussion starter' component in experimental Chapter 7, and those findings presented an early indication that encouragement can positively affect intentions to integrate. Therefore, brief interventions delivered by the HPC within the appointment may be a practical implication of the present research findings, as it appears that patients require permission or at least encouragement, from the HCP in order to use the internet to support their health decisions, and to facilitate the discussion of the information in appointments. Notably, time restrictions applied to appointments is a potential barrier to such brief interventions; however, leaflets to guide patients in their online health information searching, and the questions to ask of the information and of themselves may be a time-effective and suitable method of delivering such advice and encouragement.

Implications from this thesis thus suggest that an online intervention could be a cost effective method to encourage patients to consider and integrate the information with a HPC. Secondly, that a brief intervention delivered or provided by the HCP in appointments such as a leaflet to guide online health information searching, is a step forward to consider how multiple sources of information affect patients' health decisions. The provision of such information, may reassure patients that online health information searching is okay, and is something to be encouraged in discussions with the HCP.

### **Broader implications of the overall thesis findings**

This thesis has demonstrated how important it is to address multiple stakeholder views when considering the role of the internet in health decisions. Whilst previous research identified patient and professional perceptions individually, to knowledge, no study has combined these stakeholder experiences and perspectives, in order to develop and empirically test a solution to a problem. By exploring the patient perspective, this thesis

identified barriers and facilitators to the integration of online health information into the appointment, and through exploring the views of HCPs, this thesis challenged patient perspectives, and developed a solution to address this juxtaposition. Furthermore, by considering the views of a range of HCPs, this research thus acknowledges the views of healthcare providers who are understudied within the context of internet informed patients. For example, previous literature focuses on the view of physicians and GPs, who have more time pressures imposed on their consultation practices, and are the main port of call of many health conscious and concerned patients. Thus, previous research that employs GPs are perhaps more likely to report negative perspectives on internet informed patients, whilst this thesis reports a more holistic picture of HCPs views on the role of the internet in patients' health decision making.

This thesis has also demonstrated how important it is to consider the broader impact of the internet on patient's health decisions. Thus far, research has typically investigated how individuals with long term health conditions use online health advice to inform treatment decisions. However, Study 2 (Chapter 4) findings identified that individuals with short term health conditions primarily use the internet as a triage tool to help decide whether to make an appointment with a HCP. Although this seems a relatively innocent behaviour, current shortages of NHS resources means that appointments are often difficult to obtain, and participants in Chapter 4 reported not making an appointment to see a HCP due to lack of appointment availability, and to avoid burdening the healthcare system. When considering the importance of gaining multiple stakeholder perspectives to contribute to resolving current and emergent issues within healthcare, patient input should be considered to help address this issue caused by use of the internet as a triage device. For example, implications of this thesis suggest that professionals and patients could work together to identify placement and content of the NHS' "choose well campaign" (see Figure 8.1 below), which may encourage consumers who use the internet as a triage tool, to then consult the most appropriate health resource. Incorporating patient views to gain a more comprehensive understanding of how they use the internet to support their decision making could therefore help identify placement of important health intervention and promotion material for maximum impact.



**Figure 8.1.** NHS Choose Well campaign

This thesis also highlighted the value of employing a mixed methods approach. Qualitative methods were useful to obtain in depth insights regarding patients’ use of the internet for health related decisions; this helped to establish the different types of health decisions that are informed by online health information. Adaptation of qualitative data to inform a novel scenario based study meant that HCPs views provided a different perspective to those reported by patients, and was useful to determine differences in opinions. The use of a large-scale quantitative survey helped confirm and further explore qualitative findings with a greater, more diverse sample; this is advantageous given the limited generalisation of qualitative research due to small sample sizes, and was particularly useful in exploring the relationship between PEx, trust, empowerment, and decision satisfaction. The combination of both methodologies within this thesis has produced a more detailed picture of how online health information is used to inform health decisions, and the important factors that interplay with one another to affect decision satisfaction. Furthermore, the employment of an experimental design enabled the testing of factors identified throughout the thesis as important to decision making, in a controlled environment. Overall, this approach added to the literature by exploring patient and professional views, testing these findings with a greater more diverse sample, then examining the impact of some of these factors in a controlled experimental study.

## 8.5 Limitations

This thesis reports a number of novel and potentially useful findings, however there are some limitations to be acknowledged. Whilst this thesis aimed to capture the distributed and integrated nature of decision making, the qualitative and quantitative research methods employed merely provide a snapshot of participants' thoughts, feelings and responses at that particular time. Although it would have been preferable to follow participants along their health complaint trajectory, mapping their interactions and use of technology to inform multiple health decisions from the initial point of recognising that there were decisions to be made, to making and evaluating that decision, longitudinal research designs within the current project timeframe are impractical. Given that participants struggled to identify health decisions they had made during the qualitative studies, identifying participants at the earliest occasion of decision making to recruit for this research would have been extremely difficult. The research also largely relied upon self-report measures, which may have implications for the survey study findings. Participants retrospectively completed the online survey, concerning an occasion where they had used the internet to help them with a health related decision. Upon reflection, specifying one health decision to base survey responses on may have restricted participants' answers and may not reflect their typical online health information sourcing process. Future research should thus endeavour to identify patients diagnosed with a long term health condition, and follow their interactions with online resources over the course of the condition longitudinally, in order to map when certain information resources are used to inform different health decisions. This would also present the opportunity to examine whether the self-reflection or discussion starters components in Chapter 7 could mediate intentions to integrate the information into discussion with an HCP (as in Chapter 7) and the actual behaviour of integrating the information, in order to address the intention-behaviour gap (Sniehotta, Scholz, & Schwarzer, 2005).

This thesis highlighted that PEx persists as a key information resource to support and inform health decisions. However, previous literature discussed throughout this thesis acknowledges that PEx contains different active ingredients, such as message content (process, experience and outcome narratives) and evaluative valence, which differentially affect information search and decision evaluations (Shaffer, Hulsey, et al., 2013; Shaffer & Zikmund-Fisher, 2012). It would have been interesting to consider how each of these factors affected the pathway to decision satisfaction reported in Chapter 6. However, it

was important to explore the holistic role of PEx in decision satisfaction at this preliminary stage.

Conclusions drawn from this thesis should be considered carefully due to the homogenous samples used in the studies. Although recruitment efforts were directed toward capturing a diverse heterogeneous sample to reflect differences in the population, participants were mostly; female, Caucasian, in full time employment, and well educated. Previous research has identified that consumers who are well educated (Dutta-Bergman, 2003) and/or Caucasian (Brodie et al., 2000) are more likely to trust health websites, and individuals with low health literacy appraise online health information and websites differently (Kim, Eng, Deering, & Maxfield, 1999; Mackert et al., 2009), and make poorer health decisions than those with higher health literacy (Berkman et al., 2011). Therefore, a more diverse sample in terms of ethnicity, level of education and health literacy, and a greater representation of males would be desirable for future research to progress the findings presented in this thesis. As the present research has employed a relative youthful sample who are comfortable with using technology, it would also be of interest to explore perceptions of older adults who use the internet to inform and support health decisions, as the decline in cognitive style affects the ability to identify important and useful online resources (Agree et al., 2015; Laberge & Scialfa, 2005) and may implicate health decisions. Future research that employs a more diverse and representative sample, may contribute to health inequality research and add further context to the role of trust in online health information and health decision making.

## **8.6 Future research**

The findings of this thesis suggest that simple interventions such as the inclusion of self-reflection and discussion starters to accompany online health information can increase intentions to seek HCP intervention (Chapter 7). This thesis thus begins to explore how interventions targeting the consumers of online health information can increase integration and discussion of information with a HCP when appropriate. Future research should explore the effectiveness and practicalities associated with the delivery of a brief intervention in the form of leaflet guiding safe searching online from HCPs (e.g. chemists, GPs etc.) to patients within the medical encounter. This would contribute further to this research by encouraging action from both patients and professionals, and means that the key stakeholders involved in primary care patient care are being encouraged and supported by one another, helping to facilitate conversation. Supporting HCPs to be able to have conversations with their patients about online resources requires further

consideration of the training given to medical students and beyond as part of HCP's continuing professional development.

While the present research focused on patients who wanted to integrate information with a HCP and developed and tested an intervention to improve integration behaviours, the perspectives of patients who did not want to integrate in Chapter 4 were not explored in detail within this project timeframe. Although many participants were happy to make their own decisions without HCP intervention, future research could work to ensure these individuals are also making good, well informed decisions. One potential consideration here, is the implementation of artificial intelligence (AI) within health websites. As technology continues to embed within health services and healthcare, it is conceivable that systems will be developed sufficiently to make sophisticated, personalised suggestions to each consumer searching for online health information. Such technologies already exist in smartphone health applications such as Babylon, which conducts personalised health assessments and provides access to GPs. Basing applications around a model familiar to ecommerce in which suggestions are based on the search history of the consumer or complex algorithms that track and collate data from similar 'others', may allow more personalised or targeted points for self-reflection or next steps prompts. For example, consumers using the NHS Choose Well indicator made be told that "Other people similar to you who have looked at this sought advice from a pharmacist" or signpost to other appropriate websites. Therefore, AI could be used to present useful, credible information suggestions, and make appropriate suggestions for care interventions informed by notational guidelines, to ensure safe searching and health decisions for those who prefer to make solo decisions.

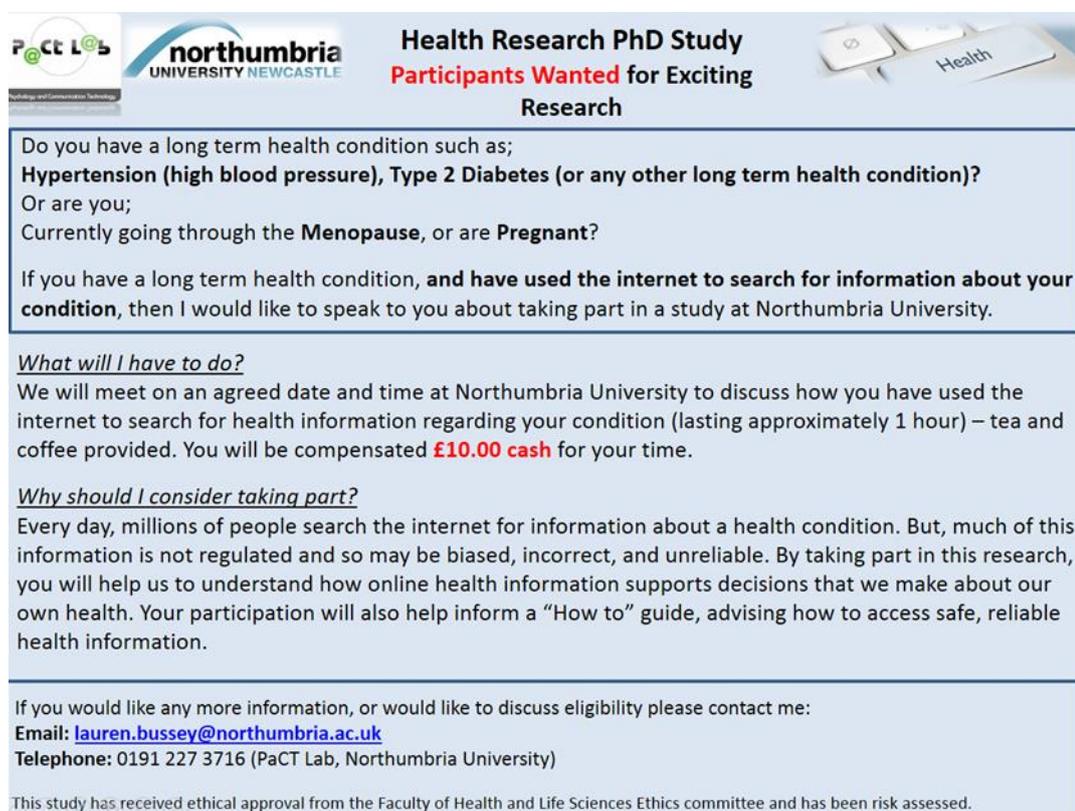
## **8.7 Final conclusion**

The main aims of this thesis, which was to examine the ways in which internet resources support health decision making across a range of health complaints, and improve and encourage the integration of online health information into interactions with healthcare professionals, have been achieved. The different ways in which the internet informs a multitude of health decisions have been identified, and this has contributed knowledge by highlighting the distributed and integrated nature of health decision making. PEx information, trust and empowerment were identified as important to obtaining health decision satisfaction. Encouraging integration of online health information into appointments with HPCs was achieved, and has contributed to knowledge by demonstrating that self-reflection and support to discuss information can increase

intentions, informed by discussions with key stakeholders. Overall, the findings from this thesis have highlighted the need to consider the complex nature of health decisions, and highlights the potential to improve the integration of online health information into appointments with HPCs using an online intervention. Implications and future research may extend findings to further inform and encourage good decision making.

## Chapter 9: Appendices

### 9.1 Study 1: Recruitment advertisement (poster)



**PaCT Lab** **northumbria UNIVERSITY NEWCASTLE** **Health Research PhD Study**  
**Participants Wanted for Exciting Research**

Do you have a long term health condition such as;  
**Hypertension (high blood pressure), Type 2 Diabetes (or any other long term health condition)?**  
Or are you;  
Currently going through the **Menopause**, or are **Pregnant**?

If you have a long term health condition, **and have used the internet to search for information about your condition**, then I would like to speak to you about taking part in a study at Northumbria University.

What will I have to do?  
We will meet on an agreed date and time at Northumbria University to discuss how you have used the internet to search for health information regarding your condition (lasting approximately 1 hour) – tea and coffee provided. You will be compensated **£10.00 cash** for your time.

Why should I consider taking part?  
Every day, millions of people search the internet for information about a health condition. But, much of this information is not regulated and so may be biased, incorrect, and unreliable. By taking part in this research, you will help us to understand how online health information supports decisions that we make about our own health. Your participation will also help inform a “How to” guide, advising how to access safe, reliable health information.

If you would like any more information, or would like to discuss eligibility please contact me:  
**Email:** [lauren.bussey@northumbria.ac.uk](mailto:lauren.bussey@northumbria.ac.uk)  
**Telephone:** 0191 227 3716 (PaCT Lab, Northumbria University)

This study has received ethical approval from the Faculty of Health and Life Sciences Ethics committee and has been risk assessed.

### 9.2 Study 1: Example of completed health complaint

#### Health Complaint

Please complete and return to the researcher at least 1 day before your agreed interview date and time.

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**Age: 23**

**Male / Female: Female**

Please briefly describe your health experience/story, telling me a little about how you have used the internet to search for information about your experience. This can include searching for symptoms, treatment options, coping resources, or however else you might have used the internet when researching your experience.

I was diagnosed with IBS in 2013/2014 after suffering from extreme stomach pains for multiple months beforehand. When I first started to get pains, I tried to research what could be causing them. Most of the time, the internet would suggest some extreme intolerance, which didn't seem to match up with my symptoms as it didn't follow a

consistent pattern. Eventually, after much persuading, I decided to go to the doctors and was told that I had IBS. I took to researching more about the subject as, whilst it is a common diagnosis, it's somewhat unusual in its testing procedure. I used the internet to find out how common it was (side note, really common), best diet techniques, how to work out trigger foods, what supplements people recommend and any other information that I could digest. I found information like the FODMAP diet and good foods to avoid. The internet provided useful resources which helped the eventual reduction in my stomach pains, and ensuring the symptoms I developed weren't abnormal or concerning.

### 9.3 Study 1: Interview guide

1. A good starting point I think is for you to give me a brief overview of your health experience(s). For example, can you tell me about the diagnosis and duration of your health experience?
2. Okay, so how did this lead to your first interactions with the internet/OSG's?
  1. Did you decide to use the internet or was it suggested to you?
  2. Apart from online information, did you source information from elsewhere as well?
    - i. i.e. medical leaflets/medical advice etc.
3. Can you remember what you researched first, and whether there was a particular place you searched for it? I just wonder whether there is a general way we search for information online, so why did you decide to search the place you searched first?
4. I wondered what your motivations were for searching health related things online
  1. Was there a particular decision you had to make and you decided to search online to help with your decision, or did you just want to feel better informed?
5. How did you decide which websites you would look at in further detail?
  1. How did you decide whether the site was trustworthy, or how correct (credible) the information was?
  2. Was there one particular website which you preferred to use? If so, could you explain to me what was it about this site that you enjoyed/liked?
6. Thinking of a time where you needed to make a decision and you used the internet to help you with this decision; could you tell me where you gathered your information from?
  1. Was it online forums/support groups, or a website such as the NHS website? *Did you join the forum?*
  2. Did you search multiple sources?
7. I wondered, out of the websites you looked at, which do you think played the biggest role in helping with your decision(s)?
  1. Was there a particular piece of information you remember most? Or did you prefer to hear about people's personal experiences rather than solid facts and statements etc.

*Online forums / websites*

1. Can you tell me a little bit about the forum you said you looked at most?
2. What made you look for this forum? (Or did you stumble across it unintentionally?)
3. What did you do after you joined/became a regular on the forum?
  - a. Did you lurk or post questions right away?
  - b. Did this change across the timeline of your illness? Can you describe the times where you posted or lurked more?
4. I wondered what your expectations of the group were? So when you posted a question were you looking for people to tell you what to do or did you want their opinions?
5. So are there times where you find yourself using the forum more?
  - a. So is it when your health is at its best or worse? What type of information are you looking for when it's poor/manageable?
6. What type of information do groups like these 'add' to the information provided by your medical professional, - What do they give you that medical professionals don't?
  - a. How important is this to you?
  - b. More specifically, how does this information aid your decisions?
7. When you ask a question on these forums, I guess you get a lot of different responses... I wonder how you sieve through them all, how do you filter out the unnecessary responses?
8. Okay so overall then, I wondered how you think the advice and experiences you read about on these forums have contributed to the decisions you have made about your health.
9. If you hadn't had access to forums, how do you think things might have been different?
  - a. Emotional support
  - b. Friendly advice
  - c. Helping with important decisions

### *Integration*

1. Okay, so having gathered information from online, what do you do with what you have learned? Do you discuss it with your family, friends, or doctor?
  - a. How does this change the relationship with your medical professional? Does it improve the quality of the meeting?
  - b. I wondered what your expectations of the doctor consultation were. So did you expect the GP to steer the consultation and you chip in now and then, or did you expect yourself to do most of the talking etc?
  - c. I wonder, how did your health professional feel about you consulting the web for information?
2. Okay, so thinking about the information you've gained from both the internet and medical professional... how do you weigh it up and make a decision?
  - a. Is the decision based solely on the advice given by the GP or online information?

- b. How much of an impact does the online information make and what type of online information makes a greater impact on your decision – personal stories from people like you, or information (stats) from people like you?
  - c. Are there some time whereby you want the GP to make the decision for you i.e. when your health is deteriorating? Why?
  - d. Do you combine them both into your decision making?
3. Once you have got information from a medical professional, do you ‘check’ it online?
    - a. Who and where do you go to do this?
    - b. Do you take information learned online and check this with the medical professional?
  4. When considering all of the different decisions you have had to make, how do you think your own emotions have played a role in your decision making and searching of information?
    - a. Have you been more likely to accept certain information when confused or upset?
    - b. Does your use of the internet change when you feel upset? E.g. do you search for support rather than information?

### *Timeline*

1. Okay, so I wondered if there were points or stages throughout the timeline of your illness where certain types of information were more appropriate. So were there certain times when you sought out personal experiences, facts etc.?
    - a. Does the information searching stop after some point? Or will you continue to search?
  2. Do you think you will always be a part of the forum or will you leave at some stage?
    - a. If your health is stable, why would you want to stay?
  3. I wondered if you could describe a time (times) where you didn’t want to make a decision.
    - a. Or, was there a time where multiple people wanted to become involved in the decision making process? i.e. family etc.
    - b. How did you go about having multiple points of view on the same decision?
- Is there anything you regret in terms of using the internet for health related information?
    - Do you regret searching/taking advice/online information?
    - Has there been a particular decision you based on online information which you now regret?
  - How could have your health decision making be improved?
    - How could the online world support you?
    - How could our medical professionals support this?

## 9.4 Study 1: Ethical documents (information, consent, debrief)



### Faculty of Health & Life Sciences

**Study Title:** Investigating the collation and integration of online health information in offline health decision-making.

**Investigator:** Lauren Bussey ([lauren.bussey@northumbria.ac.uk](mailto:lauren.bussey@northumbria.ac.uk))

**Supervisor:** Liz Sillence ([elizabeth.sillence@northumbria.ac.uk](mailto:elizabeth.sillence@northumbria.ac.uk))

**Chair of Ethics:** Nick Neave: ([nick.neave@northumbria.ac.uk](mailto:nick.neave@northumbria.ac.uk))

### Participant Information Sheet

*You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.*

*Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.*

### What is the Purpose of the Study

More and more people are searching online for health related information, e.g. symptoms, procedures, and coping advice. Therefore, it is of great interest to examine how people search for information to help them make decisions about their own health.

So, as individuals with long term health experiences have more decisions to make and are likely to search for different kinds of health information, this study will focus on individuals living with longer-term health conditions (i.e. menopause and pregnancy) or illnesses (i.e. Crohn's/Colitis, Irritable Bowel Syndrome (IBS), Hypertension, and Type 2 diabetes), and aims to understand how individuals with these conditions search for and integrate online health information when making health decisions.

### Why have I been invited?

Because you have indicated interest in taking part, are aged 18 years or above and are:

- A male or female who has a chronic health condition such as Crohn's/Colitis, IBS, Hypertension (high blood pressure), or Diabetes (T2)
- Or you are a female who is currently pregnant or going through menopause or perimenopause
- You have searched for information online regarding your health experience

If you are unsure about your eligibility, please contact the researcher who will discuss any issues or ambiguity.

### **Do I have to take part?**

No. This information sheet has been designed to help you decide whether or not to take part in this study. If you decide to take part, you are free to withdraw at any time without disclosing why. Or, if you take part and decide that you no longer want to participate in this research at any point, please contact the researcher via the contact details at the bottom of this document, quoting your participant number so that we can withdraw your data easily.

### **What will happen if I take part?**

Upon confirmation of eligibility you will meet with the researcher to sign consent forms, then you will be:

- 1) Asked to send the researcher a short paragraph describing your health experience and briefly how you used the internet to search for information (this is so the researcher can prepare appropriate questions for your interview).
- 2) Invited to attend a face to face interview lasting approximately 30 minutes, in a quiet private room in Northumberland building, Northumbria University, on a prearranged time and date. The researcher will ask you some questions regarding your use of the internet when searching for health information, and how this information contributed to health decisions you have made. The interview will be audio recorded via a Dictaphone for transcription purposes. You will have access to drawing/writing materials should you wish to use them to support your explanations.
- 3) Upon completion of the interview the recording will be saved (for transcription), you will be fully debriefed and given the opportunity to ask any questions. The researcher will then ask you if you would be willing to complete a short diary entry as and when you search for information online, or when you have made a health decision, over the next three months. If you agree to this, we will send you materials to return the completed diaries each month. At the end of the three months, we will arrange a telephone call to discuss how your internet searching might have contributed to any health decisions you have made.

Finally, you will be thanked for your participation and informed of the study findings if you have indicated interest on the consent documents.

### **What are the possible disadvantages of taking part?**

You may experience some discomfort when discussing details regarding your health experience. If so, you can take as many breaks as you need, and you do not have to answer any questions you do not wish to.

The research questions and study protocol have gained ethical clearance from Northumbria University's Faculty of Health and Life Sciences.

This research has also consulted the relevant risk assessments to ensure your safety and to ensure your participation is a positive experience.

### **What are the possible benefits of taking part?**

By participating in this study you are helping to provide important information regarding the role of the Internet in health decisions.

- Your participation could help identify areas of the internet to best place/ present certain pieces of health information, as well as highlighting which pieces of information are most important in helping make decisions.
- The collective findings could inform a leaflet detailing how to safely search online for reliable and credible health information

### **How will my data be stored and information kept confidential and anonymous?**

You will be assigned a participant number for identification purposes throughout this study. This is so that the information you provide remains anonymous.

Identifiable information such as consent forms will be securely stored in a locked filing cabinet in the Psychology Department at Northumbria University PaCT Lab. Data will be stored separately on the University U:Drive on a password-protected computer, accessible only to the researcher. All data will be stored in accordance with University guidelines and the Data Protection Act (1998).

### **What will happen to the results of the study?**

The general findings might be reported in a scientific journal or presented at a research conference, however all data will be anonymized and you or the data you have provided will not be personally identifiable. Although we may use a quote to have provided, identifiable information will not be included. Therefore, no one will be able to link this quote to you. The findings may also be shared with other organizations/institutions that have been involved with the study. We can provide you with a summary of the findings from the study if you email the researcher at the address listed below.

### **Who is Organizing and Funding the Study?**

Northumbria University.

### **Who has reviewed this study?**

This procedure has been risk assessed, and has received ethical approval from the Faculty of Health and Life Sciences Ethics committee. If you require confirmation of this please contact the Chair of this Committee, stating the title of the research project and the name of the principal investigator:

Chair of School of Life Sciences Ethics Committee,  
Northumberland Building,  
Northumbria University,  
Newcastle upon Tyne,  
NE1 8ST

## Informed consent



Faculty of Health & Life Sciences

### A GENERIC INFORMED CONSENT FORM

Project title: Investigating the collation and integration of online health information in offline decision-making.

Principal Investigator: Lauren Bussey

*please tick or initial  
where applicable*

I have carefully read and understood the Participant Information Sheet.	<input type="checkbox"/>
I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	<input type="checkbox"/>
I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.	<input type="checkbox"/>
I agree to take part in this study.	<input type="checkbox"/>
I would like to receive feedback on the overall results of the study at the email address given below.	<input type="checkbox"/>
Email address.....	

Signature of participant..... Date..... (NAME IN BLOCK LETTERS).....
Signature of researcher..... Date..... (NAME IN BLOCK LETTERS) LAUREN BUSSEY.....

**FOR USE WHEN PHOTOGRAPHS/VIDEOS/TAPE RECORDINGS WILL BE TAKEN**

Project title: Investigating the collation and integration of online health information in offline health decision-making.

Principal Investigator: Lauren Bussey

I hereby confirm that I give consent for the following recordings to be made:

Recording	Purpose	Consent
Interview voice recording and photos of written visual aids if produced by the participant	To allow the researcher to transcribe the data and for data analysis.	

Clause A: I understand that other individuals may be exposed to the recording(s) and be asked to provide ratings/judgments. The outcome of such ratings/judgments will not be conveyed to me. My name or other personal information will never be associated with the recording(s).

Tick or initial the box to indicate your consent to Clause A

Clause B: I understand that the recording(s) may also be used for teaching/research purposes and may be presented to students/researchers in an educational/research context. My name or other personal information will never be associated with the recording(s).

Tick or initial the box to indicate your consent to Clause B

Clause C: I understand that the recording(s) may be published in an appropriate journal/textbook or on an appropriate Northumbria University webpage. My name or other personal information will never be associated with the recording(s). I understand that I have the right to withdraw consent at any time prior to publication, but that once the recording(s) are in the public domain there may be no opportunity for the effective withdrawal of consent.

Tick or initial the box to indicate your consent to Clause C

Signature of participant..... Date.....

Signature of researcher..... Date.....

## PARTICIPANT DEBRIEF

**Name of Researcher: Lauren Bussey**

**Name of Supervisor: Liz Sillence**

**Project Title:** Investigating the collation and integration of online health information in offline health decision-making.

### **1. What was the purpose of the project?**

The internet has become an easy accessible information source, with many individuals searching for health advice or sharing their own health experiences online. As a result, people reading this wealth of information use it to help them make a decision about their own health e.g. deciding which medication/procedure to opt for. However, some types of information e.g. personal experiences can have a particularly large impact on the readers own health decisions, as they contain emotional information which isn't always present in other forms of health information such as facts and information websites. Therefore the purpose of this study was to investigate how individuals with chronic/long term health experiences use the internet to search for health information, and how this information is combined and then considered in their own health decisions.

### **2. How will I find out about the results?**

If you have ticked the appropriate box and provided your email/postal address on the consent form, you will automatically be sent a summary of the research findings when the results are analysed, approximately 6 weeks after taking part. If you did not do so, but wish to receive the results, please email the researcher with your contact information.

### **3. If I change my mind and wish to withdraw the information I have provided, how do I do this?**

If you wish to withdraw, contact Lauren Bussey ([lauren.bussey@northumbria.ac.uk](mailto:lauren.bussey@northumbria.ac.uk)) or Liz Sillence ([elizabeth.sillence@northumbria.ac.uk](mailto:elizabeth.sillence@northumbria.ac.uk)) with your participant number within a month of your participation. After this date, it may not be possible to withdraw your individual data as the results may already have been published. However, as all data are anonymous, your individual data will not be identifiable in any way.

The data collected in this study may also be published in scientific journals or presented at conferences. Information and data gathered during this research study will only be available to the research team identified in the information sheet. Should the research be presented or published in any form, all data will be anonymous (i.e. your personal information or data will not be identifiable).

All information and data gathered during this research will be stored in line with the Data Protection Act and will be destroyed 6 months following the conclusion of the study. If the research is published in a scientific journal it may be kept for longer before being destroyed. During that time the data may be used by members of the research team only for purposes appropriate to the research question, but at no point will your personal information or data be revealed. Insurance companies and employers will not be given any individual's personal information, nor any data provided by them, and nor will we allow access to the police, security services, social services, relatives or lawyers, unless forced to do so by the courts.

If you wish to receive feedback about the findings of this research study then please contact the researcher at [lauren.bussey@northumbria.ac.uk](mailto:lauren.bussey@northumbria.ac.uk)

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: [nick.neave@northumbria.ac.uk](mailto:nick.neave@northumbria.ac.uk)), stating the title of the research project and the name of the researcher.

## 9.5 Study 1: Transcribed interview

I: Okay so this first question is quite similar to the paragraph you sent me over email, erm I thought just a good starting point would be if you could just give me an overview of your health experience, erm you could touch upon the diagnosis and how long you've had it for.

P: Erm yes well, I've always had really oily skin and bad acne since I was thirteen or fourteen sort of when I like started my periods, erm and then I was put on Dianette which is a well-known sort of contraceptive pill to er block antigens in your body and to balance your hormones, and that really helped with me skin while I was growing up and I stopped taking it when I was twenty three cause I sort of knew I wanted to have children in the future and although you can stop taking your pill, erm, at any time and then try and get pregnant I just wanted it completely out of my system.

I: Yeah

P: I'd heard horror stories about coming off it and read a lot on google, erm forums and things like that that er once you come off it your acne can come back worse than what it was before you went on it

I: Right

P: And I did take a few month breaks in between the seven years of taking it, and I will admit by the third month it, I did get really bad spots, but I took the plunge I came off it and I did have a really bad time and I remember I had massive cysts on my back, not so much my face but on my back and I did get a bit of a hairy moustache underneath my lip, but then I think that sort of calmed down, my body did adjust, I never had flawless skin it just never happened but it was controllable erm, and then I had two children and my skin was gorgeous on my face, not my back, with my back it wasn't that I had active spots it was the scarring and the hyperpigmentation from where I've had previous acne, so it looked bad although it wasn't bad if that makes sense, erm and... my skin was fantastic breastfeeding and everything and I started my cake business when I was twenty nine and I didn't realize but my skin was starting to get really bad again, really oily a lot of like cystic lumps on my cheek which id never got before, really bad on my back erm and then I went through a separation with my husband last February and the stress of that caused us to grow facial hair, like I grew a full beard, I wouldn't say it was course or wiry like what a mans is but it was very – was downy, but it was black, jet black it was everywhere so I went to the doctors and I was crying my eyes out and she just prescribed me some antidepressants and said calm down and come back once I was calm and they would test my hormone levels and everything, erm and in that time, I was taking another pill called Yasmin cause when I was doing the cakes I noticed my skin was getting bad I thought oh I might have to start going on the pill again to try and control it erm so I was a month onto that when the hair thing happened so I was googling erm, does Yasmin make you grow hair but it was actually another drug that actually stopped hair growth and another antigen sort of blocker so I was really confused and then in the mean time I

grew hair all over the tops of my arms all over my boobs, all over my stomach erm, and I started scaring myself cause when I was googling I was reading about like losing the hair on your head, like growing... getting a man's voice having physical differences in your actual, erm in your body, so erm I continued to take Yasmin for five months and it did actually improve my skin on my face but it didn't stop the hair at all so the doctor says do you want to go back on dianette and that will completely block the hair, I didn't want to go on dianette because I know it's not – from the google research that I've done it's not the best drug to be on and you can only be on for a limited time and I've got a friend who's a doctor and she said as long as the patients healthy and is aware of the risks she will continue to prescribe it for as long as you're happy to, so as long as I keep my weight nice and my blood pressure in check and stuff I can continue to take it, but then I was googling like what supplements and herbs I can take to try and balance my hormones and suppress my antigens naturally, erm so I was researching about spearmint tea, about licorice, erm eating flaxseed to boost your estrogen levels so that stemmed to like sort of trying to control things through diet and lifestyle and it sort of become like an obsession and, but it's a good obsession because I've learned so much I literally know all about vitamins and when to eat the right food with what and what sort of counteracts another one or what you need to eat to boost the effects of a vitamin and stuff like that erm, and I have, I was considering coming of my pill and I was gonna take this thing called, erm I think it's called pol-metto, Saw Palmetto I think it's called-

I: Right

P: And it's what men take for like enlarged prostate glands but it's also known to suppress antigens so that was something I was gonna take in placement of me pill because I've always been like a natural person, I don't like taking paracetamol if I've got a headache, I'm stupid me mam just says get, take a tablet

I: No I don't either

P: I don't take anything, the only time I'll take a paracetamol is if I've gone to bed with a bad head and I've woke up and its absolutely stop and still and the sleep hasn't made it go away I think I'll take one and it'll ease it but like colds and stuff I suffer and I suffer, but erm so yeah I came across the obsession with balancing everything naturally, I searched this protein powder that I take twice a day as well and that's really good for balancing your estrogen and your progesterone I can never pronounce that one.. Progesterone

I: Oh yeah

P: And that's good for balancing that, erm, and but I've decided that I'm gonna stay on the pill for now, it's getting warmer, I feel I'm getting somewhere, so I don't wanna rock the boat so I can – ah, I've said I can probably deal with the acne because that's always been there but it's like hair because when I've removed it when I used hair removal creams- I had an epilator for my body I got folliculitis from it, and that's scarred me body from having that, and all during this as well I had a bladder infection which took ten courses of antibiotics to shift and that was unlucky as well cause id just got the infection before I broke up with my husband I think the stress just wouldn't let it heal, erm and that's something I was constantly googling and scaring myself over because it was like you know it can travel up to your kidneys and it can erm – I was in the doctors surgery and it was like my water infection put me in a coma, and I thought oh for god's sake I don't wanna read that that's what I'm here for and I had hospital visits and investigations and everything but its, that's been gone for I would say about seven or eight months now so thank god for that, but erm, I forgot what I was gonna say, so yeah I feel like I'm sort of under control now so I don't want to rock the boat but I am forever googling how to erm, sort of suppress my antigens, treat my hyper pigmentation scars, cause that's what my problem is it's not really that

I've got pick marks or anything like that it's just a red-y purple discoloration that I've got and what was frustrating, that my skin couldn't have a chance to heal because I'd get more on top of it so I'd be like, if you could just bugger off spots then it will give my skin a chance to actually heal and it would get really thick hard ones underneath the skin on my cheeks and when I was like googling and stuff like I'd be really frustrated cause I'd be like well I've done that why isn't it working, and then the things that I started to, sort searching is the emotional sides of it so then I started googling about how the mind can sort of rule the body and how yoga and mindfulness meditation can ease symptoms, so erm or positive thinking, so I read loads of articles on erm like visualizations so not only did I research like the physical sort of nutritional side-

I: Yeah

P: also like the emotional mental side as well so like literally nothing I haven't uncovered but now, my friends come up to us and say oh I've started taking this or what would you recommend for this and I'll say oh this bla bla bla and I was gonna buy a course actually it was on \*website name\* and it was reduced from like three hundred und to like twenty nine pound and it was erm, it was involving like antiaging, PCOS, nutrition, supplements and things like that, I thought ooh if I actually had a qualification I could actually say oh I've done something but with polycystic ovaries, erm, I, although I was researching about it my friend told us off saying you haven't got it or cause all the hormones came back normal all my testosterone levels were actually lower than the average women's so she was a bit baffled and said everything's fine, I was on my pill, I was on the break but I still think my pill probably influenced those results it wouldn't have been a true reading of what was really going on, so I had them done twice and it was doctor P who said I'll push for an ultrasound scan for you so I was like yes, cause some of the doctors were like dunno what's wrong get on with it erm, so I had spoke to my friend and said I think I've definitely got this but I was, like I say I was scaring myself about like how extreme it can be, erm and I had researched er that there's like, that polycystic ovaries doesn't affect everyone in the same way so it's a one size fits all, I think a lot of emphasis is put on those who are overweight, who don't have periods, and have trouble having children, I never have missed a period, I've had three pregnancies I've got two children from three pregnancies all of which were conceived in the first month of trying I just had a miscarriage the first time so that was never an issue, so erm, I was thinking well can I really have this condition cause I really don't fall into any of those categories but then I did come across something where there's a thin type and it sometimes where your testosterone levels can be normal but if there's been high levels of stress in your life it's not really the pancreas that's involved with overweight people, cause people who are overweight with polycystic ovaries its erm they are insulin resistant so sugar can get through the cells so then they produce like more of it which then affects their antigen levels and makes them gain weight, whereas with me because I've been through such a , I've always had the condition underlying, but because I went through such a stressful period it's been my adrenal glands that have been responsible for it, so in high levels of stress that's when my symptoms are gonna get really bad, so I need to make sure that I have sufficient sleep and keep my stress levels down to manage the condition and I think that's where it goes back to like the emotional side

I: Yeah

P: So erm, I think there's drug they prescribe to people who are insulin resistant and I think it's called metformin or metformin?

I: Oh I've heard of it

P: But with me, oh I can never pronounce the words, mine would be sphy-roc-ulatane, I can't pronounce that, or Spyro for short, erm cause the the sort of diabetic drug wouldn't do anything

for me cause my blood fasting sugars came back normal as well so when I went to the hospital and got the ultrasound scan and I went back to the doctor, erm and they said yes right you do have it and she gave me the spiel of like people being overweight and I already knew what she was gonna say cause I already researched it all, and I felt quite good and happy that I had read that myself-

I: Yeah

P: because I understood it more than what the doctor was giving us erm, cause I think if the doctor just explained and I didn't have that knowledge myself, I'd have went oh I dunno what that means it would have been harder to take in or understand, and I didn't wanna take spyro because its originally given to people erm who've suffered like heart problems so I think it's do with erm blood pressures and stuff and I think a lot of people who have taken it haven't had sort of, although it says there's not many side effects reported, I think a lot of them haven't had sort of, desirable sort of side effects erm I do think it makes you go to the toilet quite a lot and again like coming off Dianette its just masking the problem it's not solving it and I think hats what I wanted to do I didn't wanna mask it I wanted to actually solve the problem.

I: Okay, that's good that's a lot of information-

P: Sorry-

I: No its good gives a good background understanding so you've mentioned a few things I've already kind of earmarked throughout and thought we can talk about that more and stuff so, that's good so. Erm... how did you, would you say that being diagnosed with polycystic ovaries how did that first lead, like what was the first thing you did online or?

P: Erm.

I: Or how did it lead to using the internet?

P: Erm, I think because I'd already convinced myself that I had it, I think all of my research came beforehand, but then coming erm coming away from it that when I searched more specific to balancing my hormones, because I knew there was a hormonal imbalance with regards to my acne but I suppose when I got the diagnosis I was more specific going onto PCOS websites-

I: Yeah

P: And reading about peoples experiences about how they've managed it and I've started researching about the Paleo diet and cutting out erm like anything that's to do with agriculture and grains and just eating a very sort of meat, vegetable, fruit sort of diet, erm but I had already stopped taking dairy and all of that stuff and nothing seemed to make a difference so it was constant frustration but erm yeah after that I did sort of research more on how to, cause they say the condition is not curable but I just was trying to see it must be curable, there must be something you can do.

I: Okay, so apart from seeking information about it online was there any other sources where you got your information from? Obviously you went to the doctor and hospital-

P: Erm no I think I just bought a massive book beforehand, I think it was called the optimal, optimal nutrition and again, but at that time I was just focusing on more clearing my acne cause a lot of people said you know maybe the hair is because you've lost a lot of weight because I did lose a lot of weight, not that I was ever overweight I've always been thin but I'd lost a stone with stress, and a lot of people now say \*\*\*\*\* come off your pill cause you're not in that situation anymore so maybe it won't be as bad, but I still religiously drink my spearmint tea twice a day-

I: yeah

P: Cause I'm absolutely terrified that that'll happen again, so that's the things I dunno is it the pill is it the spearmint, is it cause I'm more relaxed is it more under control, erm but like I say the spots are just starting to stop now, and I'm literally taking zinc, erm b vitamins, vitamin d, erm I'm taking a grapeseed extract, erm I take chlorella, I take protein powder, this is like every single day, erm all to try and like just make us clearer, cause that another thing I did do I researched erm the pill and how it depleted vitamins and stuff and what you should take to restore, because with us being so natural I didn't wanna loose anything so that why I'm trying to put it back in my body

I: that's understandable yeah no problem. Okay so can you remember what it was that you searched first with regards to like using the internet for your condition? Can you remember what it was that you typed I-

P: I literally would have just put PCOS symptoms erm, coping with PCOS because I was trying to look at the emotional effects as well, erm, how to manage PCOs symptoms, so it would just be those sort of things that id type up

I: just pop them into Google?

P: Into Google search and then wait what would come up

I: Okay so I think you might have already touched upon this, so I'm just wondering obviously not from start to finish, but from the very beginning to wherever you are now, in that time that you've been searching for information about it, do you feel what you've been searching for has changed over time? So was there certain things you were looking for at the very beginning and now you're looking for something different?

P: I would say, because it was more, so specific on the acne side of things although I did have the hair growth and stuff it wasn't that originally that I was too fussed about it was why have I still got acne, why am I on this pill that makes your skin dead clear but it's not making it clearer its making me cheek acne worse-

I: Yeah

P: and so over time being diagnosed with polycystic ovaries it got more specific to that so, but I would say I would still put in the same questions but just reword them slightly or put them in a different order to see if something else would come up

I: yeah

P: So like for example, er signs of er PCOS, and then the next time I might put symptom of PCOS or erm just different wor- to see if anything different would come up that I wouldn't have seen before erm, and the amount of times I go I've read that, I've read, I've literally read them all, it is like and obsession but I think it's because I don't, the kind of personality that I am I don't like to put up with stuff, and if I can make myself better then I will and I think that's the kind of person that I am.

I: Yeah, so would you say that all of that information was quite like factual stuff like information that was put out maybe by like an organization or like a site - I know you mentioned you look at kind of like support stuff?

P: Yeah like there's support groups and forums and so I like to read into people's experiences from trying a vitamin or a supplement that when I tend to read that sort of stuff.

I: Yeah so does that stuff come a little while after the diagnosis or would you say-

P: Erm it might have come before the diagnosis but only by accident.

I: Right

P: So if its if I've been looking on an official website or a medical website, and then then next link down might have mentioned it within a forum chat and I've clicked on that, but I think after the diagnosis that's what I specifically looked on forums and a lot of the information I think comes from the acne.org I think it's called

I: Oh right okay.

P: So a lot of people go on there and there's a lot of advice on that one.

I: Yeah, okay so erm, why, why online? Why did you-

P: Its just so easy isn't it? Its whenever I get a free moment so say if I take five minutes out from what I'm doing I might have a quick search or if I'm on the bus home it's easy to get my mobile out and juts have another search and then erm, if I'm on the iPad at home with a cup of tea it's just so easy and there's just, I dunno what it is maybe it's the text or the size or whatever I just, the information I digest easier or quicker than if getting out a big book and flicking through pages.

I: Yeah okay.

P: I suppose you don't get the personal information of different people experiences in a book or anything as well it's like an online community you can get in touch with.

I: Definitely. Okay so has there been – have you been asked to make a particular decision about the condition that you've then kind of searched online for advice or information that would help you make that decisions?

P: Well when I went to the doctors I said this is what I'm taking, they said do you wanna go on spyro, and I said no, erm and she laughed cause she says you've probably already done your research on it already and I was like yeah, so I says no I'm taking this powder and I'm taking this cause I told her everything I was taking and she says if you're happy to do that that's fine with me see how you get along with it, erm so the only drug that I am sort of taking is the dianette that I'm on and she's comfortable with that and I'm comfortable with that, and like I say I finally think I'm getting somewhere.

I: Yeah you've got the combination right.

P: Yeah

I: Okay, so that was good you sort of preempted that you would need to make a choice about which medication or which drug to take-

P: yeah

I: and you kind of looked at that before-

P: beforehand

I: yeah, we'll come back to that like searching for stuff before as well that was just interesting that you preempted that that would be something you'd be asked to do so

P: Yeah

I: Okay, so going back to, you've typed whatever it was that you wanted into google and you get the big long list of websites erm how do you decide which ones you look at in further detail is there a particular kind of strategy?

P: Yeah so there's a title and then there's like a little snippet of what's included within the article or website you're gonna go on, and if there's just like one sentence or one line I go ooh, and that grabs me attention, I'll be like yeah. So say if I'm just making this up, for example, if it says do not take b vitamins it ruined my life, I'll go on there and be like oh why'd it ruin her life I need to find out, should I stop? So it's that sort of thing that grabs me attention either very positive something, somebody's said something very positive, or something's very negative-

I: Right

P: that's when I get me attention and I think right I'll click on that erm-

I: So you're not necessarily a one to kind of trawl through one by one like

P: Sometimes I'll sort of scroll up and down and see which one'll take me interest and if they're all generally the same I'll go through each one and if I'm not getting what I think I'm wanting to get from it, I'll just scroll down and come out of that one and try a new one.

I: Okay so how do you kind of decide which websites are trustworthy or that the information is reliable?

P: I don't you know, that's where I think I go wrong, and people say don't believe everything you read and stuff but obviously there's a lot of web MD or Med doctor or Net doctor or whatever you know, erm, but the websites look legit and stuff so, they just look like well presented- the articles look well written and stuff so – and I tend to know if it's very similar or bang on the same of something I've previously read and sometimes I have come across a contradiction sometimes and that puzzles us cause I think well which ones right, and I might look for a third option to see is it two out of three that goes for this argument or two out of three that goes for that argument, there's quite a lot of hard work that goes into it when I think about it.

I: A lot of eff- like a lot of effort and -

P: But, it's interesting to me though that's the thing, that's what I think keeps us hooked I find it so interesting and if I find it interesting that when information sticks.

I: Yeah

P: cause my memory is actually pretty bad, like it's absolutely shocking but certain information that's taken an interest to me personally then I can just bloom I think.

I: Yeah, okay so was there er one or a couple of websites that you tend to always go back to or that you use the most? It could be a forum as well, is there anything-?

P: I dunno there's an acne org one a lot but I think I get lost in the text so I don't really know what website I'm actually on.

I: Yeah, you jump from like, you click certain-

P: Yeah

I: Like if a word is highlighted you know its gonna take you to another page and you get lost-

P: you get lost into it, or they'll be related links at the bottom, and then I've totally, totally forgot where I am.

I: I think everyone gets into that I've done it myself, when I'm trying to look for like research articles and you're like, oh I'll go in an order I do this one first then this one but then you still like ten likes down the line on the first one.

P: Yeah

I: Okay. So when you were gathering the information for erm, the spyro was it? The-

P: I can't pronounce it it's like spyroclatine, just call it spyro for short.

I: Yeah so you preempted that you'd need to make a decision on that so where did you gain the information from about that? What kind of website was it? Was it a forum, was it an informative kind of -

P: I would say it was mainly forum for that one, erm but I did read some about just on the drug itself so it would have been a proper website but, erm... oh I'm trying to think where I might have seen it erm, I wanted to know more about the drug itself rather than the people who had taken it and what they're experiences were - did it work, what were the side effects and what was it like when they came off, erm cause coming off the drug is probably the most worrying thing

I: yeah

P: Cause eventually I'm gonna have to come off dianette and whether I do it in the winter or bottle it and do it in a few years' time I know, I just find different consequences and what'll happen but erm, but yeah for that it was definitely about people personal experienced and how long they'd been on it for.

I: So would you say that, those personal experiences and the forums would have played a larger role on your decision to kind of-

P: Yeah to see if I would take it myself or not, and there were some people who said they didn't enjoy taking it and that their problem was really bad when they came off taking it and I think that was the deal breaker, cause I thought I've already gone have to deal with dianette coming off that I don't want to have to deal with something else.

I: Yeah okay, so this is kind of a similar question really, is there a particular information you remember most that tends to stick in your mind and is it a personal experience or is it a fact or a figure or some kind of information - is there anything that always sticks on your mind?

P: What... about that particular drug?

I: Just about, I would maybe... yeah.

P: Yeah just the fact that it's er, well I can never pronounce it, it's a diuret - diuretic? It makes you go to the toilet a lot.

I: Yeah

P: It just its, it's funny with your blood pressure as well and I've got quite... well I wouldn't say I've got a diagnosis of low blood pressure cause I don't, but I know that my blood pressure tends to be on the lower side and I think for me, at the end of it I don't like forcing substances in us and just, cause I've taken so many antibiotics and I think, my immune system was so shot, like that was something else I had researched on google was like the effects of antibiotics - I had no idea they totally wipe you're gut flora, erm, and they're really not good for you, and I had taken ten courses within like I dunno how many months but it wasn't in a long time, so that's something else I've learned I need to build up so I take probiotic now so that's just something else that I've

learned about drugs and stuff and I know that I don't wanna be really ill in the future and need antibiotics and be immune, because obviously the antibiotics won't work and when I was using them erm, oh it was just a horrible experience, so yeah that was something else I had learned.

I: Okay so the next few questions are quite, I've got them noted down to be like related to like the forum kind of websites you've been on, but they are easily adaptable to websites if you feel it applies a little bit more, so I'm wondering if you could tell me a little bit about the forum that you relied on, looked at most, or if there wasn't one in particular just-

P: I definitely would say the acne one acne.org and there was a new one erm, that I went on since I was diagnosed and it was called... eeh it's so cringey, I think it was like, it's so cringey soul sisters but sisters with "CY" -

I: Oh yeah

P: Like cystic, so erm, yeah that was one that I went on quite a lot so I would probably say them two the most ones. Other ones I can't remember because I don't really take notice of what I'm actually looking on I just read the text

I: the information.

P: Yeah

I: Okay so how did they kind of look on screen? Were they presented quite well?

P: Yeah they were they were just like in boxes so really well, you were able to follow, there was always a line between the response and the question things like that so dead dead easy to follow.

I: Yeah and have you actually like joined any of these forums or?

P: No I just... I just stay silent in the background and be a ghost reader.

I: So have you ever posted any questions or is it just a case of-

P: Just reading what they are.

I: Yeah so is there any reason why you decided you would join or post a question in particular?

P: Erm I dunno cause like when I was pregnant and stuff I joined like baby forums and stuff, I think it's because I want the information quickly that I just wanna read then move on to the next thing to read and erm I think once me thirst for knowledge has been totally quenched then I might wanna join and then just have general chats and stuff, and say oh how do you feel about that but at the moment, I just want like the information to read and a lot of the time they've already asked questions that are sort of on my mind-

I: Yeah

P: Er cause obviously that's what the question is that I've put in so a lot of the questions that I would maybe put myself have already been answered

I: already there

P: Yeah

I: Okay. And would you say that's been quite consistent throughout-

P: yeah I would say, its juts like the odd response that gets to you like oh no this did not work for me and it wasn't very good then just when I've like convinced myself that somethings gonna be beneficial I go oh well, that's made us doubt it now-

I: Yeah

P: But I just have to tell myself that's one person out of so many people

I: Yeah. Okay so although I know that you've just said there that you've never kind of posted a question about PCOS or er, so I was just wondering what your expectations were when you saw a discussion or a thread that was like answering the question that you wanted the answer to? What were you kind of expecting the responses to be erm, if it was kind of your question was regarding oh should I take this particular drug, like were you kind of expecting people to say like yes take it, it was really good or erm kind of not have that kind a forthright in out into -

P: Yeah I don't think I – I don't think I expected anything, I think its hope, so it's not like an expectation I'd say its hoping that it's the answer that you want or hoping that it's not gonna be as bad as what you think it's gonna be or you're hoping this would work so yeah it, not having an expectation on anything it's trying to be positive and hoping that you're gonna read what, its hearing what you wanna hear basically.

I: Yeah, so you weren't necessarily looking for people to say do this, do that, but you were looking for them to say what their experience was and then you would decide yourself whether or not it was worth pursuing?

P: Yeah definitely.

I: Okay so have you found yourself in certain times searching for health related information more? Has there been certain periods where you've been on it and others where you've dropped off or?

P: It's been pretty consistent I would say, erm definitely dead heavy erm, when I first got diagnosed but now I'm sort of more satisfied, and like I say because now I can feel results like my skin and stuff I'm not pushing it for er, for as hard as what I was em but that just because I'm good at the minute, but if I was to wake up tomorrow and have like a billion new spots I'd be like fucking hell, ooh sorry about me language!

I: It's alright

P: What can I do now, what am I missing? But again its controlling me mind and trying not to stress because if that is part of the problem of what I'm going through I have to stop my stress, so maybe if I try to refrain from doing it and just have that acceptance things might naturally improve. But I think it's because I'm so interested in it and it's like ooh well what do you do for like twenty minutes on the bus so you just end up doing it anyway, do you know what I mean?

I: No it's understandable.

P: It goes like Instagram, Snapchat, Facebook, Google, YouTube, then you go and start and do it all over again so, you just end up doing it.

I: IT just becomes part of your routine-

P: Yeah

I: Okay so what kind of, what would you say, the information online adds to that that's already been given by your doctor or?

P: I think online's better because what I found when I went to the doctors is that the internet wasn't wrong, the doctor actually said what I had researched about there being different types of polycystic ovary and how that drug wouldn't be good for me because I didn't fall into that category and it was nice to hear her say that I was like yes that's what I read that's what I understand but obviously she doesn't go on to elaborate whereas the internet does

I: Yeah

P: Cause I've got all the time in the world to go and elaborate on it

I: Yeah

P: So that's where it differs, they both give us the same information whether the doctor gives us a snippet where the internet gives us the world of what I needed to know, whether it's all correct I don't know but judging by what she said-

I: Yeah like I mentioned before the internet's got all the extra erm, like personal experience information

P: yeah

I: whereas obviously one doctor telling you you fall under a particular category that fine it's the same but obviously the internet give you extra explanations which you've obviously based some of your decisions from-

P: yeah

I: as well so.

P: I mean I know its not like the same with everyone, everyone's gonna go through a different experience and I shouldn't really take that as facts just because someone had a dodgy stomach with something, but if it's a common pattern that's what I mean-

I: yeah

P: then I'll think, ooh yeah this is like a common occurrence like everyone says dianette makes your skin worse when you come off it and people would like start their threads with like er is it true I have been hearing horror stories, and I know from my personal experience that yes it is true so that's how I know that you can't take this is as like the bible what people are saying it might not affect me like it affected them but, because I know that coming off dianette it was horrific for me that people were speaking the truth so it is possible.

I: Yeah, so would you say the information online is as reliable and trustworthy then as that of your doctor?

P: I would say so, I mean you don't, if you've got like chest pains and that and you put it in goggle and its saying you've got a heart attack like, then you know that, that's not very likely, so yes the internet can make you panic, it can probably cause a lot of health anxiety amongst people, but if you're strong in your head and you're clever you know not to panic about things that you've read, and don't get us wrong there are some things that like my hearts sunk and I've thought, ah that has upset us, but then I have to remind myself just take one day at a time and just because I have this condition it doesn't mean I will lose my hair it doesn't mean I will definitely have this, it just means that it's a possibility the same of people reading their side effects, it's a possibility, but difference why I've made a decisions on other people's experiences drugs is like am I coping well as it is without it, do I really need it, and put myself erm at risk of... when I have to come off it again so that's where that's is.

I: Okay so you mentioned before that obviously you're not, not really one for posting a question but you'd find the thread or the question then read the responses-

P: yeah

I: Do you kind of have any erm, like methods of reading all of those responses? Erm or is it kind of similar to like the Google search do you look at everything and see what-

P: its once I'm like satisfied, so like say if like say someone's put a question up and say they've got about twenty responses

I: Yeah

P: I like get to the fifth response and if its more or less the same, and then I'll flick through further towards the bottom and if I've got the information that I'm happy with then I'll stop and come off, so I wouldn't probably read all of like the responses or if like a discussion or heated argument is brewing between two people like well I took this and I didn't find that and then I might continue with what I'm reading sort of thing.

I: Mhm yeah okay. Okay so overall then just rounding off the forum kind of aspect, how do you think the advice and experiences that you've read about on those forums have contributed to your decisions that you've made?

P: yeah definitely, I've just, I think like when I go with the majority so if the majority said this was bloody awful, I'll think oh nah I'm not gonna take it, but it's the same with anything you could take a supplement that'll make your hair dead shiny, you read the reviews and say oh that products really good it makes everyone's hair dead shiny I think I'll buy that, or if it went bloody doesn't work waste of money and then you go oh I won't bother that's the same thing with like medication and stuff like that.

I: Okay so if you hadn't had access to these forums then how do you think things would be different would there be for you?

P: Id probably just go along with what the doctor said.

I: Yeah, do you think that would have been like a bad thing? Do you like it that you got-

P: Yeah but, it would have been because there was me taking antibiotic after antibiotic not knowing that it was really not good for me health, even me mam said why are they prescribing you more antibiotics \*\*\*\*\* you're only meant to have three lots in a year, and I had had ten erm, and then I got thrush in my mouth and everything off them so you just say yes yes, and yes they've done you know many years studying and stuff like far more you know cleverer than me on my forums and that but, it's your body and you should be in charge of your own body and I think if you've got the knowledge and you've done the research yourself you can make better choices and not have someone say take these they'll make you feel better-

I: Mhm

P: If there's an alternative way to do it, or a more natural way why can't or why should you not try and do that erm because doctors are very medical and are very sort of narrow minded with that they just see everything from a medical point of view whereas you get other people who have come from the holistic sort of natural background and some people might think that's airy fairy just bloody take the pills but you know, ah I suppose I am a little but airy fairy like there's natural medicine in the world, everywhere you go erm, and we didn't always have doctors and medicines there's alternatives to everything and as I say like with medicine your just masking the problem

you're not treating the problem and eventually I will have to come off dianette and then I'm gonna only have to deal with the aftermath naturally anyway if I can't take anything else so that's why I'd rather just make those choices now rather than sort it out now so I can continue just looking after myself.

I: Yeah, okay, cool.

P: Don't, don't get us wrong like doctors are mint and they save lives and everything, I'm no dissing doctors (laughs).

I: No it's been quite a similar consensus throughout most people I've chatted to as well, and I mean my erm, my, what would I call her, my cousins wife, she's done like a nutritional science degree and she works in schools now and she's in charge of like health and nutrition and she's got erm a blog called \*blog name\* and on there is it's a wealth of like healthy recipes she doesn't eat any meat she eats pretty much all plant based stuff and like she's very much like always like more or less reiterating the stuff that you've said-

P: yeah

I: Like about the zinc and stuff like that like oh eat this food for zinc levels it's good for this this and this and she's actually like a dietician as well so she's got like plans available that are for like if you were losing weight, or there's ones for actually reducing anxiety there's different foods that do different things-

P: yeah

I: So I totally get where you're coming from that there is actually natural things that can help rather than just like you say just masking it with drugs or medication-

P: absolutely.

I: Yeah.

P: I think cause I read about the pill like just depleting, it depletes vitamin c, magnesium, zinc all of your B vitamins and it raises your candida levels in your body and stuff like that so just by knowing that, I know I can try and supplements to try to replenish what I've got just to keep everything... and doing that will probably make it easier coming off me pill because I've set me, me er, cause I think your B vitamins do help with hormonal balances, I know it's got that on the packaging on the box, but like your pill raises your copper levels so your zinc levels are just completely squashed and you need zinc for acne, so there's a lot of contradictions that I found, it was taking away a lot of the natural things that would improve your acne so just seemed a bit, a bit bizarre.

I: Yeah okay so, this is kind of what I had earmarked at first, when you discussed at first erm, about the condition so I was just wondering how, after you've gathered the information from online, what do you then do with what you've learned? And one of my little side points was do you discuss it with family, friends, a doctor cause obviously you said before that you -

P: Yeah I did sort of mention to me doctor what I had erm, what I had learned, I talked to my friends a lot my family I don't really talk about it with cause they just go oh shut up, erm, but erm I talk about it with, I've got a funny story actually, talk about it with health people who work in like health shops and stuff like erm we were talking about turmeric with this woman and she went to say something and I like said it in replacement of what she was gonna say like oh yeah take it with black pepper cause it acts as a catalyst, she was like yes it does, cause I read about it I feel like, god I need to keep me mouth shut cause I'm telling people how to do their jobs and I just, I

should just pretend I don't know anything, but erm, I actually was talking to me health condition in \*High street health store\* and ended up going on a date with the person I was telling, so that was quite funny!

I: that worked out quite well!

P: Well actually it didn't the date was a disaster but, well it wasn't a disaster I just didn't fancy him and, it was nice to go on a date anyway to get out and about.

I: Yeah of course.

P: So that was quite funny and that was just like talking about me knowledge and everything I had learned.

I: Yeah, and I think do you find people are more like, you get more out of like doctors and nurses and other people when you... when you know more about it as well?

P: Yeah because you sort of you know an answer so you'll deliberately ask it to see if they'll say the same answer or to elaborate on anything that you've just said as well so yeah I definitely do, cause obviously I got that conversation from my doctor about what medications, and I bet you've researched that already and yes it's good for this and no it might not be good for that, erm, and the same when I went for me ultrasound I was able to talk more to the sonographer or... I think that's what you call them, erm so yeah you feel like because you, you know the answer you still ask it to see if they're gonna say the same thing as what you've, what you've read.

I: Okay, so when you initially or other times that you've been to the doctors or GP what kind of are you expectations or how do you think the consultations gonna go? Do you think you'll kind of put in both fifty-fifty in terms of like discussing and -

P: Yeah

I: And in terms of the final decision or, do you expect that the doctor will, you'll sit there say what's wrong and then they will just-

P: I think it depends what type of doctor I get, I get three, one not bothered about, the other one yeah you can get some good responses from her where she's active and she's like no this is interesting and absolutely and shell give an explanation why somethings happened or whatever, but the best doctor is doctor ? who I have and he's the one who'll really take the time to discuss the reasons why somethings happening and why he thinks somethings happening what it can go and lead onto and he's the one who said we'll get you an ultrasound scan because he knew there was something wrong, and when I went to, once I got my results from the hospital they said make an appointment at the doctors cause you need a proper diagnosis from them, once you've got all that information together erm, it was doctors ? Who said oh doctor X has put a note on your records saying he erm, he suggests the such and such theory which is basically other words of having the thin version of polycystic ovaries and that's when I was like yes, that's what I researched, that's what I know about so, and that's when she said or the metaforin, or metaformin drug won't be good for you because this is what we suspect that you have, and then that's when I was like yes I've researched it and I agree, whereas if I hadn't have done that research beforehand id have probably went what what do you mean like, is there a different type, like what?

I: Yeah

P: And because they only have a ten minute slot they can't answer all questions so I probably would have went online anyway.

I: Yeah, so they seem quite open for you to be searching stuff online-

P: Yeah yeah absolutely fine, yeah, I think they'd tell us if I was being a bit ridiculous or that's not necessarily true... they would, they would tell us, in a way I would then maybe take the doctors word for it-

I: Yeah

P: If they were like no, that's that's actually wrong, but there's one thing that my doctor did say she said you don't need to be taking supplements if you're eating a healthy diet and that's like a contradiction that I've read on the internet and a health book that was just upstairs when the book man came, and it was about what to eat and what to supplement when you've got certain conditions

I: right

P: and it was erm, there was one for the contraceptive pill and it says take your vitamin C and B vitamins erm so that wasn't just on the internet that was a published book but the doctor said no you don't need to take anything as long as you're eating a healthy diet.

I: Yeah, cause they expect that you're gonna get that from whatever you're eating but obviously some people don't have a healthy diet obviously then they supplement so.

P: I think with the B vitamins it's just a constant battle like you just go through them like nobody business so you just have to keep on putting them through.

I: Okay so what's your kind of take on erm, everyone or most people searching for health related stuff online before going to a medical appointment?

P: Oh I would sort of encourage it, but I would say to them erm, just be careful and don't panic erm, cause obviously if you're researching lumps and bumps and stuff that's when people start... and in that case say, the difference with me is that it wasn't a life threatening condition.

I: Yeah so that was gonna be my next question, do you think it depends-

P: Yeah I think it depends on what it is, I think if it was something like a life threatening condition then I would probably be cautious, not because the information's inaccurate just that why would I wanna cause extra anxiety.

I: Mhm

P: Sometimes I think not live in denial but maybe not know too much information in some situations, like my mams just been diagnosed with breast cancer and the first thing she said to her was do not go on Google, that was the first thing they said to her.

I: Aw... that's interesting cause I bet it's so overwhelming depending on what it is that you have or might have, I think I would definitely tend to agree that would ring true if you're trying to research for, you know you kind of had an idea that you had a chest infection or something like that and you pop that in Google and normally you get like NHS choices up or something like that and you can kind of see like yeah I've maybe got that, but if you had something like oh I'm not quite sure what, like you say like a lump you're already thinking this could be something quite bas so yeah, I can-

P: Mm, so with the things I was sort of searching was sort of like maintenance or maintaining my condition or how to improve it but yeah it wasn't as if yeah it was gonna kill us polycystic ovaries can be a killer, yes I've upset myself and scared myself with what you can get, so in a way yes it

has upset us but, then I just have to calm down say no that doesn't mean for definite I just have to remember for definite and keep a positive outlook that might change.

I: Yeah and how do you feel then about having all of that information? Obviously you've read some upsetting stuff, on the whole do you think yeah okay I've read some upsetting stuff but I've read some good stuff, but I feel quite at ease that I've got all of this knowledge and I know what could potentially happen so if the worst was to happen, I mean touch wood that it won't-

P: You're prepared

I: that you're already kind of-

P: Yeah

I: it's not gonna be a punch in the face like well, I dint know that was gonna happen.

P: Yeah no definitely I feel that not everything I've read is what I've wanted to hear, but I'm glad that I know about it and I am aware of it so I can prepare for it, and as well just reading stuff about like support and like knowing that it doesn't make you strange, it doesn't make you less of a woman or anything like that, so there's those feel good factors as well where people are like no its fine, it can be hard to maintain and things like that but you know you're fantastic you know, that sort of affirmation sort of things.

I: Yeah that's good. Okay so this is erm... might have already touched upon this as well actually, so thinking about the information you've gained both from your doctor and the stuff you've read online, how do you kind of make a decisions based on that information? Do you take into account both of them equally or do you rely more heavily on one than the other when making a decision?

P: I'd say like the doctor has got the like, the qualification and stuff but, erm, I think it would be the internet that makes the decision because the doctor would propose it, I would read about it and then say nah it's not for me, unless you know like my life was at risk then I would take the doctor's advice.

I: Yeah

P: I would take it, but because this is something that I'm trying to manage alternatively and my life's not a risk from it then I can sort of say nah I'm not gonna do what the doctor says I'm gonna try another way-

I: that's good that's interesting

P: Erm but then I suppose if it was a cancer and that like, then I would take me chemo and I would do all of that stuff-

I: Yeah cause you read those stories about that erm, was it a parent the other year who wouldn't give, like wouldn't allow their child to have chemotherapy or radiotherapy or something like that, they were gonna take them to another country and do this other thing, or something like that, or they wanted, or you hear about these people who try and like cure themselves naturally by eating just like fruit and stuff like that so obviously there's a lot of-

P: Yeah and I think in extreme situations I'd say no, I need to the doctors to help us I'll just do anything that they say, but in saying that though id still try and look after myself, since me mams found out that she's got breast cancer I've done a lot of research on chlorella and that's really good for chemotherapy and radiotherapy so I've bought her chlorella tablets cause she doesn't wanna take the powder like I take it, she doesn't wanna taste it but it's been apparently it's fantastic for your white blood cells and stuff so I've give her that and that's something I've

researched and that was a common thing again I look for common factors and every website that I went on said it was fantastic for chemotherapy and radiotherapy it just helps your body cope better with it so your body has a better sort of response and just having that extra weapon so that's would I would do if I had something like cancer I would do everything the doctors were telling us but I would google health and stuff like that just for the extra boost in my wellbeing if that makes sense.

I: Yeah, definitely, erm... so you just said there that you'd probably rely a bit more on the internet in your particular case, would you say the type of information you rely on more was the experienced based information?

P: Erm, When making a decision to take something or not, but for actual facts and stuff I'm happy to just take information from a website or, but again I will only take it if its common, if it's a common occurrence between articles so if I don't find a bit of information again then I may not remember it or focus on that but if it's like oh this says this and this says that and then the next article or personal experiences says that relates to that, that's when I make a decision yes its true its actually true (laughs) I don't know if it's still true.

I: Yeah I get what you mean. Okay so you've just answered that one as well... think you might have already answered this one as well, it was juts whether you've ever tended to check information that your GPs told you and then check it online?

P: Yeah

I: Cause I know a lot of people do it the other way around like they might they might feel a bit funny about trying to second guess a GP cause they know best and typically it is like the older people who'll be like no doctors right, I'll just do what the doctor says so, but is it a case of sometimes yeah the doctors said something like the erm, I can't remember what it was before but then you've gone and maybe checked it had been like no-

P: I would do it beforehand and I would do it after, I would do it both ways I would say so.

I: Okay. And you also touched upon this which I thought was interesting as well so I just wondered whether erm, I was kind of thinking along the lines of how do peoples like emotions play in their decision making, I know you mentioned before like obviously you've took like quite a holistic approach and erm like a natural approach ad you've mentioned mindfulness and yoga, that can be all linked to emotions and bodily states and what else, erm so I was just wondering have your emotions do you feel played a role in like your decision or your ability to make decisions?

P: Yeah I think cause...

I: And that could be decisions or general searching for information.

P: Yeah, yeah I think I mean I've come across things like I say that's really upset us and I'm like devastated but then I can easily just click on the next link and find something that's motivational and uplifting erm, but I think I've read so much stuff now that I'm totally immune.

I: Yeah.

P: I don't get upset and I dot get happy, don't get us wrong I still get happy and think aw that's a nice thing I've just read there and aw yeah its canny so yeah but I don't think I get upset like cause I've literally exhausted everything I've – well I wouldn't say I've exhausted everything cause I could probably find another way to ask the same question but erm, but yeah no I don't think I get as emotionally affect by what I read now.

I: And what about kind of the other way around? So has there been times where erm, you might have been feeling poorly or upset or anxious or anything like that and has that affected the way that you've searched for information?

P: Yeah I think if I'd come up with a new load of spots I'd be like oh for god's sake man, why, maybe me questions would get more angry like why is my acne persistent why won't it go away and its questions like that that bring up more forum type of responses as opposed to websites, but erm, but yeah so I'll, so if I'm having a particularly bad skin day that's when I might get aggressive with my google search and be like why won't it just bugger off, but yeah.

I: And do you think that would make you more erm, likely or less likely to accept information that was on there. So if like you say you've done a bit of an angry search and someone's, you've read something like try this, would you be more accepting to that information-

P: Yeah cause I think desperation as well, like I'm at the end of me tether so probably yes.

I: Okay and would you say, in those cases where you maybe were feeling maybe more upset or emotional one day do you find yourself searching for support or would you say you would get that from your family or-

P: No I don't talk about it with family because they're just sick of hearing it my friends are sick of hearing it as well so I think I just keep it to myself now, or I might just put it in like, squeeze it into a little sentence like oh I read that such and such can help this so I'm gonna try that and they'll be like eh what are you like is that something else that you're trying, I'm like yeah, so I tend to keep it to myself now.

I: Yeah but it's not necessarily a thing that you've searched online like, oh I'm feeling this this and this-

P: No no, I think erm... I think I have searched like the emotional impacts of having acne and stuff I've googled that erm and just like people being upset but the thing is though I have to remind myself that I don't have the worst case scenario and I think that's something else I've googled, like people who've got more sever put it in perspective-

I: Yeah, yeah

P: Erm but like I say now it's not really, acnes not really a problem now it's more of I'm just dealing with the scarring now but I'll still get spots every month, like I'll get a new one but it's it has, that's why I'm saying now I'm starting to get it under control so I don't want to come off it and rock the boat I might just have the summer of enjoying what I've got then saying that its unpredictable like I say tomorrow or next week I could break up, beak out in a few of them and that's when I'll go oh god why now, erm but now I'm just, because now I've researched it online like derma rollers and stuff I've bought a derma roller -

I: Oh yeah

P: And so that's something that I'm gonna be like once I definitely don't have any active acne because that like punctures holes in your face and it causes your body, sorry your blood to produce more collagen so it takes away the pigmentation marks it can fill up the pick marks and stuff so erm, but you can't have active acne cause it'll spread the infection so I'm just waiting 'til I definitely don't have anything, which is more or less now and then I can use it and you use it once every two weeks for three months and you see results, cause I was gonna get it done at a proper skin clinic with a micro needling equipment it was gonna cost us eight hundred pound whereas this derma roller at home cost thirty, so you just disinfect it yourself and do it at home.

I: Yeah it might be worth a shot isn't it? If tis gonna work and save eight hundred quid.

P: Yeah.

I: Okay so you've mentioned this as well, on the whole how much do you like to be involved in the decisions about your health?

P: A hundred percent.

I: Mhm and that would be all aspects like in the discussion of treatment, remedies and lifestyle related-

P: As long as it was something that, like a condition what I've got, as I say if it was something more serious I would-

I: Yeah

P: Let the doctors take control and I'd probably refrain from knowing too much information.

I: Yeah okay-

P: Only google things I think could help but not google the things that is gonna make us poorly of what I'm taking or something like that.

I: Okay so in terms of the information that you've searched for, how much would you say of that searching is just purely for your own benefit and knowledge rather than you were searching in order to, because you had to make a decision and you were kind of researching?

P: Erm I'd say majority is just for my knowledge but, it's just little things like drugs proposed to us or I'm contemplating coming off the pill, that's when the research has helped us make a decision.

I: Yeah okay, erm do you think that your health seeking of information online will stop after a certain point or if everything's under control? Or do you think like yourself because you've got such an interest in it do you think-

P: I'll always google food and nutrition I'll always do that because it's something I absolutely love, but as far as like polycystic ovaries and stuff I think that'll probably die off for now erm, cause I think, I think if I'm having a bit of a shit day like if I feel a bit eugh, that's when I might go on a forum and have a read see uplifting comments things like that, but as far as the actual condition is concerned I think I have goggled it to death and I'm well aware of it now so I think now I have to keep an eye on my mental health and just make sure I keep my spirits lifted to just to help symptoms of the condition... there's a lot, I mean polycystic ovaries is so common I think one in ten women have got it, and that's not the issue because some women go around completely normal and have an idea that they have it and have no symptoms whatsoever, and I'm really blessed that I've had two children cause that's the first thing my ma said is well you've got them two kids, a lot of people with it, I think it's the number one of infertility problem that we've got, but I think what was upsetting for me was like why have I got little spots over my face, why have I got spots over me face and why am I like growing a beard I think that's just devastating because anything that affects your like femininity is gonna be, is gonna be upsetting so it's a common problem it just doesn't affect everybody in the same way so it just depends, and if I lost the hair on my head like I'd be absolutely devastated, I least you can remove hair but you cannot easily grow it back.

I: Okay so I don't think there has been but you touched upon this before, but has there been a time where you personally not wanted to make a decision about your health? I know you said

maybe if it was different condition and it was quite serious or life threatening then you would be quite willing to relinquish that decision to the GP but, having polycystic ovaries now has there ever been a time where you've kinda not wanted to make a certain decision or-

P: No I've always wanted to make a decision but like, sometimes I'm not happy with them like I'll have to stay on the pill but then I try and convince myself like you know it's doing the best it can, if its, if it's bad now your skin can you imagine what your skin would be like if you weren't on it, so I sort of like, try and convince myself that the decision that I've made is the right one.

I: Yeah and I think I'd definitely does make an impact if you can be kind of in charge of that decision, and like you say although you can't be one hundred percent happy with it I think it's really empowering that you've kind of took the time and effort to learn about it and make that decisions and I think it does definitely help with the healing process -

P: Yeah

I: I mean things I've read in relation to like my PhD so far, all of , most doctors are about patient empowerment now, the government is encouraging people to take more of an active role because it does help the healing process and obviously that stuff that you're passing onto your mam as well now taking the extra powders and -

P: she would always be like shut up and take your pills or whatever but I think this is the first time she's been in the situation where she actually said I'll do anything, I will eat the right foods and anything to give my body the best sort of defense you can possibly get so she actually turned around and said \*\*\*\*\* what can you advice, what can you help us with and I felt good that I was able to say yes mam you should make sure to take this and so that and for mother's day I got her like a fruit and veg basket erm, so she had like loads of vitamins in her basket so just like to make herself feel good because it think nutrition and emotional wellbeing just plays such a massive role on your overall health.

I: For sure definitely, and final two questions just to round everything up, erm so firstly is there anything you regret in terms of searching the internet for health related information?

P: No I don't regret anything.

I: Yeah

P: I was upset sometimes but like I'm glad that I, I'm in the know cause if it was to happen I'll know it's happening, there's a chance, but not to be totally miserable with it and just think well it's not happening now so.

I: Yeah okay and finally this has been a tricky one for people to answer actually, erm is there any way that your kind of health decision making could be improved? Is there any kind of part of the process or, is there any parts of the internet that you think could be improved to be more supportive or from the doctors point of view or?

P: I think it's more the doctors point of view I think, I don't think it's their fault I think they have such a short time to say, its only doctor \*\*\*\* who doesn't give a hoot about that, his clinics are like always running behind but it's because he gives people the chance to talk and he explains things so, yeah I think the internet can give you so much information when you wanna read it how you wanna read it erm, how often you wanna look at the same bit of information but the doctors don't have that time and I think maybe if you don't want to your sort of forced a little bit-

I: Yeah

P: But sometimes the doctors do say ooh read into this or I'll suggest this website like that has happened like over the past when I've been to the doctors and sometimes they've printed some information out as well about, oh what was it, I think it might have been foods, this is when I was much much younger for a different problem, so they have been quite helpful that was more helpful back then I think they're a bit more strict now so yeah maybe just the doctors but, no I think the internet is fine the way it is, you just have to be strong to take the information on that's all I will say.

I: Yeah it can be a dangerous place sometimes.

P: Yeah

I: No that's fab so that's all of my questions I had, I'll just stop this.

## **9.6 Study 1: Transcription Notes (example)**

Uses a Facebook forum that is private and asks a lot of questions on there – it's only a small group of women who left another forum which was filled with negativity.

Very good with computing, checks a lot of things on the sites for credibility – is a web designer.

Searching internet is good because it's there for you when you want it at whatever time, and the anonymity of it allows you to seek out information without feeling "stupid" which you might feel asking your midwife all these questions.

Kicks Count FB page influenced decision to get scan.

Searched symptoms online – pregnancy then morning sickness – sticks to credible websites like NHS, Netmums and Bounty

Searched morning sickness medication before seeing GP so she could be on the same level

Looked up stats around weight gain, morning sickness longevity and miscarriage likelihood, then turned more toward social sites which she said are trustworthy, but can be negative experience too

Uses web because it's familiar, and searches symptoms instead of asking midwife, similar to P4 for fear of being overanxious or feeling silly – feeling judged.

Website in DM – Kicks count – read info on here then decided to act, didn't work so rang midwife – was right thing to do – read case stories on their FB group and I has saved lives.

Goes onto explain how reading experience trumps NHS because you get specific information that is honest

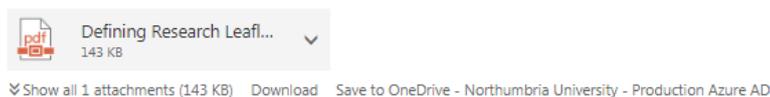
Gave example where she took information she learned from forums and decided to talk to her midwife again and request blood tests







## 9.10 Study 3: Permission to recruit using NHS general communications email



Hi Lauren

Thanks for sending this through – it's one of the disadvantages of a generic decision tool in that it doesn't really capture the correct outcome for qualitative studies.

I would say your work is research as it aims to generate new knowledge - you will I assume want to publish the findings / disseminate them and part of that implies that the results are applicable to a wider audience than just those who participated in the work. On that basis it's research rather than "evaluation" or "audit".

I've attached an explanatory document that defines all three types of enquiry (research, audit, service evaluation).

You have two options

1. As you won't have access to NHS staff details (it's not in the public domain) you could try to avoid having to seek R&D permission for access to NHS staff info and you could recruit through open advert in public places or through the Trust general communications email. This way their approach to you and participation is entirely voluntary and permission from us to contact people directly isn't needed. You'd have to make it clear that the interviews will have to be undertaken in their own time and not on NHS premises etc etc. Only with these stipulations can you undertake the research without formal NHS permission
2. If you wish to directly contact individual staff groups then you would need NHS permission. You would need to submit an application to HRA for review even though NHS Ethics isn't needed. Once participating Trusts receive this HRA permission they then confirm their willingness to participate. Your university will guide you through the process of making an HRA application.

*With best wishes*

## 9.11 Study 3: Scenarios

### Scenarios

The interviews from study 1 and study 2 informed the design of study 3 in which we applied a vignette-based role-play approach with general practitioners and healthcare professionals in the UK to elicit reflections on and insights about patient's use of internet resources in their decision making.

We gave participants five scenarios and asked them to think out loud as they were reading them. We asked for general comments on the case, and how they would use the information supplied by the patient.

Firstly, thank you for taking time to take part in this research. If I could just reiterate that all details you provide are anonymous and private. Any places, names, or establishments mentioned will be removed from your data to further ensure anonymity.

I thought a good place to start is if you could tell me a little bit about your career in healthcare so far (training? Placements? Current role and what this entails)

### **Medical training**

Were you given any formal or informal training regarding patients searching online?

What guidance were you given?

Were there any solutions or techniques for dealing with such encounters?

### **Scenario 1:**

Betty has just arrived for her appointment. You have only met with Betty a handful of times and she informs you that she has been doing some reading on the internet regarding her [diabetes] care.

- What is your first reaction to this scenario?
- What would you say to Betty?
- Would you consider Betty's internet searches into your discussions with her?
  - Would you be open to discuss or dismiss the information?
  - Would it depend on the source of the information?
- How do you think you could use her internet searches to help in any decision making around Betty's care
- How could you take this forward – what would be your next steps or advice to Betty in regards to her information sourcing?
  - Probe – directing Betty to look at specific web sources, steering her away from web resources?

### **Scenario 2:**

Debbie was diagnosed with Diabetes 3 years ago. She has recently started to search online for information about her diabetes to help her understand and manage the condition better. She looked on the NHS Choices site and saw some useful information on there about diet but felt that she needed additional help. She printed the page from NHS choices and made an appointment to see you. At the appointment, she says she feels more knowledgeable about the condition now and has a few, well thought through questions to ask you. In addition, she asks if she can receive further help from a dietician.

- What is your first reaction to this scenario? – what goes through your mind?
- What do you say to Debbie? How would you (if at all) include Debbie's internet searches into your discussions with her?
- How do you feel about the role of the Internet in Debbie's decision-making about her health?
  - Probe reaction to NHS choices
  - Would you consider the information differently if it were from a different (less reliable) information source?
- How would you take this situation forward – what would be your next steps?

### **Scenario 3:**

Sophie is one of your patients and has been taking medication you prescribed for her to help with her [IBS]. She has been taking it for some time but has felt no improvement. She decided to go online and found a support group for people with IBS. Whilst on the site, she read other people's experiences of this medication for the same issue. Sophie has decided to stop taking the prescribed medication because she read that other people had

stopped taking the medication as it hadn't worked for them either. In her next appointment with you she tells you what she has decided and why.

- What is your first reaction to this? – what goes through your mind?
- How do you feel about what's Sophie's done
  - Probe - how do you discuss this with her?
- How do you feel about the role the Internet has played in Sophie's decision-making?
- How would you discuss the information Sophie tells you about with her in the consultation?
- How would you take this forward – what would be your next steps?
  - Probe - What advice would you give to Sophie?

#### **Scenario 4:**

Luke has ulcerative colitis and a family member has suggested trying a treatment that worked well for them. Luke looks up more information online and becomes quite excited about the idea of trying this medication and so makes an appointment with you. When he mentions the treatment he doesn't say anything about his research online but talks about 'other people' he knows that have tried it. When you tell him that the treatment isn't available he seems disappointed and embarrassed and leaves quite abruptly.

- When a patient like Luke suggests a treatment or procedure based on other people's experiences - what's your first reaction? – what goes through your mind?
- Why do you think Luke is reluctant to disclose the source of his information with you?
  - Probe – if he had disclosed would that have made you think differently?
  - Probe - would the source have made a difference?
- How do you think you could/would use Luke's internet searches to help in any decision making around Luke's care
- How could you take this forward – next steps?
- 

#### **Scenario 5:**

Brian has come to see you about his recent symptoms. He has been looking online at a number of different websites to try and understand what his symptoms might mean. He comes to you with a tentative, possible diagnosis and explains why he thinks it might be the case. He refers to the information he has found online including a number of patient experiences from online support groups. He is clear that he doesn't believe everything he reads online but shows you the sites and the information he has read and then asks for your opinion?

- What is your first reaction? – what goes through your mind?
  - Probe – do you like patients like this – why/why not?
- What do you say to Brian? How do you discuss the internet information?

- Probe - What extra questions do you ask – what information do you want to know?
- How do you think you could/would use her internet searches to help in any decision making around Brian's care
- What next steps would you suggest to Brian in terms of his use of the Internet and decision making?

Generic Questions:

How do you feel about patients searching online?

How does it affect the decision making?

Good or bad? What does this depend on?

Do you feel that patients searching online is useful before seeing you?

Do you feel that patients searching online is useful after seeing you?

Can patient searching affect the doctor-patient relationship?

Good or bad? Why is this?

How would you recommend patients present the information to you (if so at all)?

### **9.12 Study 3: Interview and analysis notes (example)**

GP for over 3 years. Open to patients coming into appointments informed by internet information, particularly when it develops understanding, and can create conversation and discussion – people are taking responsibility for their care which is good. Also considers the credibility and source of the information brought in – willing to look at the info with the patient too. A little weary of some forums as she isn't sure patients receive appropriate support– stick to markers of confidence such as the NHS logos. Mentions keeping referrals down – something I hadn't considered. When patients come in demanding it can put you on the back foot. Sometimes wonder if patient searching at home is because he as a GP has missed something – feels she has a big responsibility. Making a decision before coming in can be off-putting. Thinks that maybe patients don't always come in open and honest as they feel embarrassed to challenge the role of the GP or that the information is not correct. Believes as a GP you need to be flexible and adapt to each patients individual style. Describes the importance of being open when discussing information integration (p. 16). (p17) discusses how the internet helps patients to clarify decisions to be made ect. Signposting to information sources and resources. Can impact the relationship positives and negatives.

## 9.13 Study 4: Survey questions

### Health Information Online Survey

**Q4 Instructions** When completing this survey we would like you to think about a time when you have used the internet to help you with a **health decision**. For example, online information may have helped you decide whether or not to see a healthcare professional, to stop, take, or change medication, to buy a health related product, to try home remedies/treatments.

**Q5** To what extent would you describe this health issue as **long-term**? By long-term we mean any health issue (diagnosed or undiagnosed) lasting **more than 3 months**, some examples are: Heart Disease, Inflammatory Bowel Disease, and Polycystic Ovary Syndrome.

- A great deal (1)
- A lot (2)
- A moderate amount (3)
- A little (4)
- None at all (5)

**Q6** To what extent would you describe your health issue as **short-term**? By short term we mean any health issue **lasting up to 3 months** e.g. coughs, colds, flu, aches, pains, vaccinations.

- A great deal (1)
- A lot (2)
- A moderate amount (3)
- A little (4)
- None at all (5)

**Q7** To what extent did you consider this health issue to be serious?

- A great deal (1)
- A lot (2)
- A moderate amount (3)
- A little (4)
- None at all (5)

Q8 To what extent did you consider this health issue to be sensitive?

- A great deal (1)
- A lot (2)
- A moderate amount (3)
- A little (4)
- None at all (5)

Q9 What was the **MAIN** decision you were making?

- Treatment related (1)
- Product/ Service related (2)
- Health related administration (informing the DVLA, information to support life insurance etc.) (3)
- Changing doctor/ doctor surgery/ hospitals (4)
- Diet/ Lifestyle related (5)
- Deciding to have/ not to have further medical tests/ examinations (6)
- Deciding whether to see a Healthcare Professional (by this we mean a doctor/ GP, chemist, nurse, consultant, specialist etc.) (7)

Q10 In relation to your decision making, what was your **MAIN** motivation in going online

- Someone told me to (1)
- Health professional told me to (2)
- To find information from other people (3)
- To double check information (4)
- To see more options (5)
- To get a broader perspective (6)

Q11 Thinking about any one site that you visited during your health information searching...

Q12 What was the name of website (if you remember)

Q13 What was the website address (if you remember)

---

Q14 Who do you think owns the site?

Charity (1)

Commercial organization (2)

Pharmaceutical manufacturers (3)

Health Insurance group (4)

National Health Services/ Government (5)

Educational institution (6)

Other (please specify) (7) \_\_\_\_\_

Q15 Please respond on the scales below to show how much you agree that each statement describes the site you used

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)
The language on the site made it easy to understand (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The site helped me understand my health issue better (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The site was easy to use (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The site told me most of what I needed to know (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The layout was consistent with other sites (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information appeared to be prepared by an expert (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information seemed to be offered in my best interests (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information came from a knowledgeable source (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information appeared to be impartial and independent (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The site was free from advertisements (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information seemed objective (i.e. no hidden agenda) (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The information seemed credible (12)	<input type="radio"/>						
The site was owned by a well-known organization (13)	<input type="radio"/>						
The site featured familiar logos (14)	<input type="radio"/>						
The site had a professional design (15)	<input type="radio"/>						
The site had an attractive design (16)	<input type="radio"/>						
The site gave reassurances about how they used your information (17)	<input type="radio"/>						
I trusted the information on the site (18)	<input type="radio"/>						
I trusted the site (19)	<input type="radio"/>						

Q17 The following questions relate to the presence of **patient experiences** or personal accounts of other people on the site. Personal experiences may be present in blogs, forum messages, narratives or testimonials.

Q18 Please rate to what extent each statement describes the site you were looking at.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The site contained accounts of other patients experiences (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was a chance to share my experiences (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There were opportunities to interact with other people on the site (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
On the site I saw a wide range of experiences rather different to mine (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The site offered powerful accounts of health experiences (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

It felt like the advice was tailored to me personally (6)	<input type="radio"/>				
On the site I was offered the chance to see experiences from people just like me (7)	<input type="radio"/>				
The site contained contributions from likeminded people (8)	<input type="radio"/>				
I was able to contribute to content on the site (9)	<input type="radio"/>				
The personal accounts on the site were written by people similar to me (10)	<input type="radio"/>				
I found personal accounts that reflected my own experience (11)	<input type="radio"/>				
I found personal accounts that were relevant to my condition (12)	<input type="radio"/>				
There were opportunities to gather information from the personal accounts on the site (13)	<input type="radio"/>				
The personal accounts contained advice for readers (14)	<input type="radio"/>				
The personal accounts provided social or emotional support (15)	<input type="radio"/>				

Q19 The information on the site made me feel...

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Powerless to do anything about my health issue (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Empowered to do something about my health issue (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More positive about making future decisions about my health (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Able to cope with having this condition/ cope with this health issue (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reassured (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Optimistic (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In control (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confused (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q20 The information on the site helped me...

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Explain what the issue means to others (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Know where to go to get the medical help I/my family need (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Know what could be gained from each of the options available to me (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understand the reasons behind my health professionals' suggestions (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understand what I can do to change how this issue affects me (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make plans for the next steps/ decisions (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q21 Thinking about the information or advice on the site please rate your agreement with the following statements by selecting the appropriate response.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I have checked the advice on other websites (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have checked the advice with other sources (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 Having read the online information did you then decide to go and see a healthcare professional (either straight away or at some point soon afterwards)?

- Yes (1)
- No (2)

Q23 Please identify to what extent you agree with the following statements.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The online health information helped me decide to see a healthcare professional (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The online health information helped me feel more confident about seeing a healthcare professional (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted to prepare for a visit to the doctors (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I told the healthcare professional that I had searched online for information (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I brought the information I found online to the appointment with the healthcare professional (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt the knowledge I brought from the internet supported my discussions with the healthcare professional (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My knowledge from the internet positively supported the communication between myself and the healthcare professional (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I asked the healthcare professional questions based on the internet information (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I asked the healthcare professional questions without revealing I had searched online (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The healthcare professional reacted positively to my online searching (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 Thinking about the appointment with your healthcare professional about your health complaint, please identify to what extent you agree with the following statements.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
My healthcare professional collaborated with me in arriving at my decision (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare professional considered my knowledge and experience when providing me with information relevant to the decision (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information provided by my healthcare professional was necessary to help my decision making (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare professional treated me as an equal rather than as a client (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare professional listened to me attentively and patiently (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare professional encouraged me to discuss my concerns/information (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare professional made me feel at ease when discussing my concerns and fears (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q25 As you decided not to see a healthcare professional, please rate to what extent do you agree with the following statements:

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The information online helped me to decide not to seek further medical help (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could make the decision on my own without seeing a healthcare professional (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt confident to make the decision on my own (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt confident to make the decision after reading the online information (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q26 To what extent do you agree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I didn't want to bother the healthcare professional (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't want to wait for an appointment to become available (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't want to waste the healthcare professional's time (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The doctor did not know much about the health issue (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not trust the doctor (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe healthcare professional doesn't want to hear my opinion/ consider my knowledge (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't know how to bring up the information (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't feel confident to discuss the information (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't want them to know I had searched online (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Q27 Decision Satisfaction

Thinking about the decision you made based on information from the website, to what extent do you agree with the following statements:

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I was satisfied with the decision I made (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was happy with the decision I made (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was confident with the decision I made (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Without the internet my health decision making would have been less satisfactory (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe the internet positively contributed to my decision (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe reading other peoples experiences was most useful in my decision making (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe factual and statistical information was most useful in my decision making (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q28 Without the internet my health decision making would have been...

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)
More time consuming (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Less easy to manage (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More overwhelming (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Q29 Future Decisions

Please indicate to what extent you agree with the following statements.

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
I intend to use the internet as part of future health decisions (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In future, I intend to take health information to my healthcare professional (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I intend to use patient experiences for future decision making (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I intend to use factual sites for future decision making (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Q30 Demographics

Q31 How do you view yourself?

- Male (1)
- Female (2)
- Prefer not to say (3)
- In another way (please specify) (4)

Q32 At the time of completing this survey how old are you? (Years)

\*Please only enter a number into the box below e.g. 35

---

Q33 What is your employment status?

- Full Time (1)
- Part Time (2)
- Retired (3)
- Unemployed (4)
- Student (5)
- Other (please specify) (6) \_\_\_\_\_

Q34 What is your marital status?

- Single (1)
- Married (2)
- Cohabiting (3)
- Civil Partnership (4)
- Separated (5)
- Divorced (6)
- Widowed (7)
- Other (please specify) (8) \_\_\_\_\_

Q35 What is your ethnicity?

- Caucasian (1)
  - Latino/Hispanic (2)
  - Middle Eastern (3)
  - African (4)
  - Caribbean (5)
  - South Asian (6)
  - East Asian (7)
  - Mixed (please specify) (8) \_\_\_\_\_
  - Other (please specify) (9) \_\_\_\_\_
- 

Q36 What is your highest level of education?

- Less than High School/ Secondary School (1)
- Secondary School (2)
- A level or equivalent (3)
- Vocational/technical (4)
- High School/ GED (5)
- College (6)
- Bachelors degree (7)
- Masters degree (8)
- Professional/ Doctoral Degree (MD, PhD) (9)
- Other (please specify) (10)

Q37 Approximately how many years have you been using the internet?

\*Please only enter a number into the box below e.g. 4

Q38 Did you go back and visit the site whilst you were filling in this survey?

- Yes (1)
- No (2)

#### 9.14 Study 4: Correlation of trust outcomes

		Correlations	
		I trusted the information on the site	I trusted the site
I trusted the information on the site	Pearson Correlation	1	.736**
	Sig. (2-tailed)		.000
	N	196	196
I trusted the site	Pearson Correlation	.736**	1
	Sig. (2-tailed)	.000	
	N	196	196

\*\* . Correlation is significant at the 0.01 level (2-tailed).

### 9.15 Study 4: Presence of PEx PCA (load onto 1 factor)

<b>Component Matrix<sup>a</sup></b>	
	Component 1
The site contained accounts of other patients experiences	.817
There was a chance to share my experiences	.825
There were opportunities to interact with other people on the site	.831
On the site I saw a wide range of experiences rather different to mine	.746
The site offered powerful accounts of health experiences	.842
It felt like the advice was tailored to me personally	.664
On the site I was offered the chance to see experiences from people just like me	.875
The site contained contributions from likeminded people	.883
I was able to contribute to content on the site	.806
The personal accounts on the site were written by people similar to me	.889
I found personal accounts that reflected my own experience	.889
I found personal accounts that were relevant to my condition	.882
There were opportunities to gather information from the personal accounts on the site	.867
Please rate to what extent each statement describes the site you were looking at. -The personal accounts contained advice for readers	.858
The personal accounts provided social or emotional support	.868
Extraction Method: Principal Component Analysis.	
a. 1 components extracted.	

## 9.16 Study 4: Mediation outputs from PROCESS

Run MATRIX procedure:

\*\*\*\*\* PROCESS Procedure for SPSS Release 2.16.3 \*\*\*\*\*

Written by Andrew F. Hayes, Ph.D.    www.afhayes.com

\*\*\*\*\*  
\*\*\*\*

Model = 4

Y = Ds

X = PEX

M1 = Positive

M2 = Negative

M3 = NewVersi

Sample size

196

\*\*\*\*\*  
\*\*\*\*

Outcome: Positive

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3753	.1409	.3773	31.8127	1.0000	194.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	3.2067	.1163	27.5731	.0000	2.9773	3.4360
PEX	.2136	.0379	5.6403	.0000	.1389	.2883

\*\*\*\*\*  
\*\*\*\*

Outcome: Negative

Model Summary

R	R-sq	MSE	F	df1	df2	p
.1442	.0208	.7360	4.1190	1.0000	194.0000	.0438

Model

	coeff	se	t	p	LLCI	ULCI
constant	2.5995	.1624	16.0050	.0000	2.2792	2.9198
PEX	-.1073	.0529	-2.0295	.0438	-.2117	-.0030

\*\*\*\*\*  
\*\*\*\*

Outcome: NewVersi

Model Summary

R	R-sq	MSE	F	df1	df2	p
.2110	.0445	.3895	9.0416	1.0000	194.0000	.0030

Model

	coeff	se	t	p	LLCI	ULCI
constant	3.5876	.1182	30.3640	.0000	3.3546	3.8207
PEX	.1157	.0385	3.0069	.0030	.0398	.1916

\*\*\*\*\*  
 \*\*\*\*

Outcome: Ds

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5317	.2827	.3972	18.8226	4.0000	191.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	2.9526	.4335	6.8117	.0000	2.0976	3.8076
Positive	.2193	.1066	2.0579	.0410	.0091	.4295
Negative	-.1946	.0625	-3.1142	.0021	-.3178	-.0713
NewVersi	.2703	.0943	2.8675	.0046	.0844	.4563
PEX	-.0263	.0421	-.6250	.5327	-.1094	.0567

\*\*\*\*\* DIRECT AND INDIRECT EFFECTS  
 \*\*\*\*\*

Direct effect of X on Y

Effect	SE	t	p	LLCI	ULCI
-.0263	.0421	-.6250	.5327	-.1094	.0567

Indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
TOTAL	.0990	.0267	.0493	.1552
Positive	.0468	.0225	.0087	.0987
Negative	.0209	.0133	.0019	.0570
NewVersi	.0313	.0150	.0082	.0705

\*\*\*\*\* ANALYSIS NOTES AND WARNINGS  
 \*\*\*\*\*

Number of bootstrap samples for bias corrected bootstrap confidence intervals:  
 5000

Level of confidence for all confidence intervals in output:  
 95.00

----- END MATRIX -----

Run MATRIX procedure:

\*\*\*\*\* PROCESS Procedure for SPSS Release 2.16.3 \*\*\*\*\*

Written by Andrew F. Hayes, Ph.D. www.afhayes.com

\*\*\*\*\*  
\*\*\*\*

Model = 4  
Y = Ds  
X = TRUST\_OU  
M1 = Positive  
M2 = Negative  
M3 = NewVersi

Sample size  
196

\*\*\*\*\*  
\*\*\*\*

Outcome: Positive

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3018	.0911	.3992	19.4412	1.0000	194.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	2.4756	.3069	8.0664	.0000	1.8703	3.0809
TRUST_OU	.2210	.0501	4.4092	.0000	.1222	.3199

\*\*\*\*\*  
\*\*\*\*

Outcome: Negative

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3114	.0970	.6787	20.8380	1.0000	194.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	4.1011	.4002	10.2484	.0000	3.3118	4.8903
TRUST_OU	-.2984	.0654	-4.5649	.0000	-.4273	-.1694

\*\*\*\*\*  
\*\*\*\*

Outcome: NewVersi

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3702	.1371	.3518	30.8148	1.0000	194.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	2.3348	.2881	8.1044	.0000	1.7666	2.9030
TRUST_OU	.2612	.0471	5.5511	.0000	.1684	.3540

\*\*\*\*\*  
 \*\*\*\*

Outcome: Ds

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5424	.2942	.3908	19.9059	4.0000	191.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	2.4511	.5072	4.8327	.0000	1.4507	3.4515
Positive	.1993	.1001	1.9910	.0479	.0019	.3967
Negative	-.1755	.0629	-2.7895	.0058	-.2996	-.0514
NewVersi	.2297	.0963	2.3862	.0180	.0398	.4195
TRUST_OU	.1021	.0545	1.8722	.0627	-.0055	.2097

\*\*\*\*\* DIRECT AND INDIRECT EFFECTS  
 \*\*\*\*\*

Direct effect of X on Y

Effect	SE	t	p	LLCI	ULCI
.1021	.0545	1.8722	.0627	-.0055	.2097

Indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
TOTAL	.1564	.0372	.0921	.2382
Positive	.0440	.0246	.0058	.1068
Negative	.0524	.0234	.0170	.1106
NewVersi	.0600	.0294	.0090	.1263

\*\*\*\*\* ANALYSIS NOTES AND WARNINGS  
 \*\*\*\*\*

Number of bootstrap samples for bias corrected bootstrap confidence intervals:  
 5000

Level of confidence for all confidence intervals in output:  
 95.00

----- END MATRIX -----

## 9.17 Study 5: Health scenario

For the purposes of this study, please imagine yourself in the following scenario:

You have recently discovered a lump in your breast during a routine breast self-exam. Following this discovery, you made an appointment with your GP to have the lump examined. After examining the lump, your physician arranged for you to have a mammogram, which is an X-ray of your breast. The radiologist reading the mammogram characterized the lump as suspicious and recommended a biopsy of the lump. Your physician then referred you to the local Breast Centre, a facility specializing in the diagnosis and treatment of breast cancer, to have the lump biopsied. A breast biopsy involves removing a small section of breast tissue for examination. After the biopsy, the tissue sample was sent to a pathologist, a person who diagnoses disease by examining organs, tissues, bodily fluids, etc. The pathologist's job is to determine whether the cells were malignant (i.e. cancerous) or benign (i.e. not cancerous).

You returned to the Breast Centre to discuss the results of the biopsy. You were informed that the lump was malignant, and you were referred to an oncologist at the Breast Centre for treatment. An oncologist is a physician who organizes the care of cancer patients. After reviewing the reports from the biopsy and mammogram, your oncologist informed you that you have early stage breast cancer. Typically, early stage breast cancer is treated through local therapy – one of two types of breast surgery. Local therapy is often followed by systemic therapy, such as chemotherapy, which is a course of treatment that travels through the blood stream, affecting cells all over the body.

There may be several treatment decisions to make; however, the oncologist explained that the first decision you must make is what type of surgery to have. The other decisions will be made after viewing the pathology report from your surgery. Based on estimates of the tumour size from the biopsy and mammogram, the oncologist informed you that you have two surgical options. In some medical situations, there is a clear right answer, and your doctor can tell you what is best to do. In other situations, like with early stage breast cancer, there are different choices that are reasonable. What is “best” depends upon how you feel about the good and bad things that might happen with each choice. In this case, you do have a choice.

There are two surgeries designed to remove cancer from your breast. Mastectomy is a surgery to remove the entire breast. Lumpectomy is a surgery to remove only the breast tumor and a border of healthy tissue around it. This surgery is followed by radiation therapy to kill any cancer cells that may be left in the breast or breast area.

Whether you choose mastectomy or lumpectomy with radiation will not make a difference in how long you live. However, there are other important differences between the surgeries. The decision you make will depend on how you feel about these differences, which include:

- The length of your hospital stay
- The discomfort you experience after your surgery
- The length of your recovery time
- Whether or not you need radiation therapy
- Whether or not you want to have a second surgery that will re-create the removed breast (this is called breast reconstruction)

- The chance that your cancer may come back in the breast or breast area (this is called local recurrence)
- How your body looks after surgery, i.e. your appearance

How you feel about these differences is important, because chances are very good that you will live with the result of your decision for a very long time. (To help you make this decision, we will present 4 written stories, by breast cancer survivors. The women share their experiences with Mastectomy surgery or lumpectomy surgery and radiation) Please remember that your surgical choice will not affect how long you live. Because survival after the two treatments is the same for your cancer, your decision should depend on how you feel about the other important differences between the two surgeries. Review any information you wish; there is no time limit. After reviewing the desired information, please indicate whether you would prefer to have mastectomy or lumpectomy and radiation. After you have made your decision, we will ask you several questions about your decision making process.

### **9.18 Study 5: Example of patient narrative story**

#### *Process*

At first all I could think about was dying, and I was focused on choosing a treatment that would minimize my chances that the cancer would return. I never wanted to have to make this decision again. I decided to look online, to see if there was anybody talking about how they made their decision and what things they took into consideration. After reading more about the mastectomy and lumpectomy treatments, I realized that there were other factors I needed to consider which might even be more important to me in the long run. Although it was important to consider which option had the least chance of the cancer returning, I started thinking about what I would look like after each surgery. I was worried about how attractive I would feel and what my husband would think of my body. So I spent a lot of time reading about the two surgeries and looking at pictures of women who had had lumpectomies and mastectomies. I took all the information booklets from my oncologist's office and spent a lot of time researching the surgeries online.

I also thought a lot about the amount of effort each treatment would take. Radiation therapy would require a large time investment, and I have two young daughters. I really did not want to miss out on many weeks of their life driving back and forth from the hospital and resting. I knew I would regret missing their football games and ballet recitals, and I really just wanted the treatment to be over quickly. However, I'm still young, and it felt really important to me to keep my breast too. Looking back, I am very happy with the process I went through to make my decision because I really took the time to consider all of the relevant factors, not just whether the cancer would return. I totally understand why another woman might select mastectomy, but the benefits of lumpectomy really matched what I valued.

#### *Experience*

Well, knowing I was having surgery, the first thing I expected was to be in a lot of pain, but it really wasn't as bad as I thought it would be. I was certainly uncomfortable for a

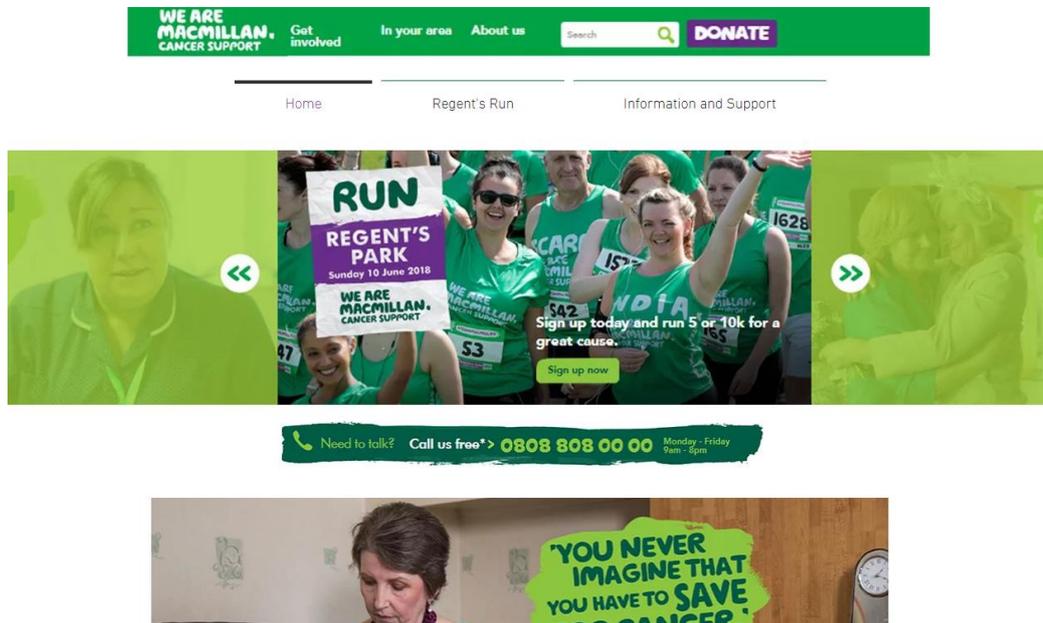
few hours after the surgery, but that was expected and what the surgeon had explained beforehand, but there was virtually no pain just some discomfort. When I was discharged from the hospital later that evening, my doctor sent me home with some pain medication, but I only had to take a few doses.

Shortly after having the surgery, I began five weeks of radiation therapy. I had to go to the hospital once a day for five days a week for treatments that took about half an hour each. I knew this wasn't going to be the easiest five weeks of my life, but I expected the radiation treatments to be manageable, and they were. Although it was initially a pain to go drive to the hospital every day, it quickly became part of my routine. I wouldn't say the radiation sessions were easy, I felt a dull aching sensation in my chest during most of the sessions. But, really, the procedures weren't painful, more uncomfortable, and they were over fairly quickly. I began to get tired by the end of the five weeks, but taking an hour long nap each day really helped.

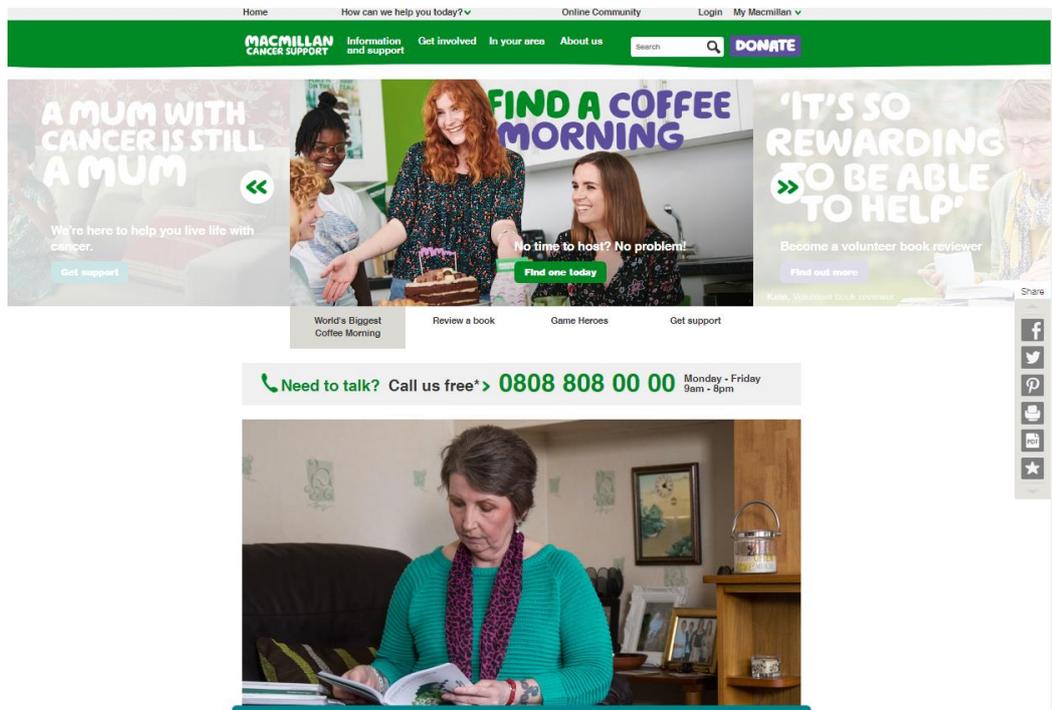
I think the thing I was most concerned about was how my breast would look after the lumpectomy. I was worried that I would look very lopsided, which would make me feel very self-conscious. But, I was surprised to find that the changes in my appearance really didn't bother me like I had expected. The one breast is clearly smaller than the other, but I honestly don't think that anyone other than my husband or myself can tell. I am happy that I chose the lumpectomy, that the cancer was gone and that I still had both breasts. And, my breast does have a scar from the surgery, but it really feels like a badge of honour. It is kind of my little private reminder that I am a breast cancer survivor. On the whole I feel very happy with the decision I made, and the overall experience of the treatment was not as bad as I had initially expected.

## 9.19 Study 5: Comparison of websites

Website developed for study 5:



Screenshot of Macmillan Cancer Support website:



## 9.20 Study 5: Survey questions

Q7 Please indicate your treatment decision

- extremely likely to choose lumpectomy with radiation (1)
- likely to choose lumpectomy with radiation (2)
- not very likely to choose lumpectomy with radiation (3)
- undecided (4)
- not very likely to choose mastectomy (5)
- likely to choose mastectomy (6)
- extremely likely to choose mastectomy (7)

Q8 Thinking about the patient stories you read, we would now like you to evaluate your treatment decision

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Somewhat Agree (4)	Agree (5)	Strongly Agree (6)
I am confident in my ability to make an informed choice (1)	<input type="radio"/>					
I thoroughly considered all of the relevant factors (2)	<input type="radio"/>					
I am prepared to make this treatment decision (3)	<input type="radio"/>					
I am confident I am aware of the relevant factors (4)	<input type="radio"/>					
I have a good understanding of the information presented (5)	<input type="radio"/>					
I am likely to obtain information from additional sources (6)	<input type="radio"/>					
I am satisfied with my decision process (7)	<input type="radio"/>					
I am satisfied with my treatment decision (8)	<input type="radio"/>					
I have a clear feeling about what it is like to have a lumpectomy and radiation (9)	<input type="radio"/>					
I have a clear feeling about what it is like to have a mastectomy (10)	<input type="radio"/>					

Q9 Please respond to the following statements:

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Somewhat Agree (4)	Agree (5)	Strongly Agree (6)
I feel comfortable in discussing the information with my healthcare professional (1)	<input type="radio"/>					
I feel confident discussing the information with my healthcare professional (2)	<input type="radio"/>					
I feel comfortable in summarising the information with my healthcare professional (3)	<input type="radio"/>					
I feel confident in summarising the information with my healthcare professional (4)	<input type="radio"/>					
I feel better able to ask my healthcare professional questions (5)	<input type="radio"/>					

Q21 Please respond to the following statements:

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Somewhat Agree (4)	Agree (5)	Strongly Agree (6)
At points, I had a hard time making sense of what was going on in the stories (1)	<input type="radio"/>					
My understanding of the characters is unclear (2)	<input type="radio"/>					
I found it difficult to follow the main point of the story (3)	<input type="radio"/>					
I found my mind wandering while reading the stories (4)	<input type="radio"/>					
While reading the stories I found myself thinking about other things (5)	<input type="radio"/>					
I had a hard time keeping my mind on the stories (6)	<input type="radio"/>					
The story affected me emotionally (7)	<input type="radio"/>					
My emotions varied whilst reading the stories to match those of the storyteller (8)	<input type="radio"/>					
I felt like I could empathise with the characters in the stories (9)	<input type="radio"/>					

Q10

Demographics

Q11 How do you view yourself?

- Male (1)
  - Female (2)
  - Prefer not to say (3)
  - In another way (please specify) (4)
-

Q12 At the time of completing this study old are you? (Years)

\*Please only enter a number into the box below e.g. 35

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Q13 What is your employment status?

- Full Time (1)
- Part Time (2)
- Retired (3)
- Student (4)
- Unemployed (5)
- Other (please specify) (6) \_\_\_\_\_

Q14 What is your marital status?

- Single (1)
- Married (2)
- Cohabiting (3)
- Civil Partnership (4)
- Separated (5)
- Divorced (6)
- Widowed (7)
- Other (please specify) (8) \_\_\_\_\_

Q15 What is your ethnicity?

- Caucasian (1)
- Latino/Hispanic (2)
- Middle Eastern (3)
- African (4)
- Caribbean (5)
- South Asian (6)
- East Asian (7)
- Mixed (please specify) (8) \_\_\_\_\_
- Other (please specify) (9) \_\_\_\_\_

## Chapter 10: References

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