Farnood, Annabel (2021) *The effects of online self-diagnosis and health information seeking on the patient-healthcare professional relationship.* PhD thesis.

The effects of online self-diagnosis and health information seeking on the patient-healthcare professional relationship

Annabel Farnood, BN, MSc

Thesis submitted in fulfilment of the requirements for the

Degree of Doctor of Philosophy

School of Medicine, Dentistry and Nursing

College of Medicine, Veterinary and Life Sciences

University of Glasgow

December 2021

Abstract

Background: Internet connectivity is spreading around the globe, and in some countries, connectivity is almost universal. When connected, the internet user has before them, an unparalleled information resource. Among the billions of web pages, are many devoted to health information, from academic resources to patient online health forums. In increasing numbers, patients are turning to these resources for information. Healthcare professionals including nurses, find themselves relating to increasingly knowledgeable patients and the very nature of the relationship is changing. Understanding this change and its consequences is an important research task and as part of this endeavour, this thesis reports on the effects of patient online self-diagnosis and health information-seeking on the patient-healthcare professional relationship and medical authority.

Methods: First, a mixed methods systematic review examines and synthesises the current literature on the effects of patient online self-diagnosis on the patient-healthcare professional relationship. Second, a qualitative descriptive method was adopted for investigating heart failure online health forums. Finally, online semi-structured interviews were conducted with a sample of 16 patients and 15 healthcare professionals, to gain their perceptions of the use of the internet for seeking online health information. Data were analysed thematically, and Normalization Process Theory provided the underlying conceptual lens to inform analysis.

Findings: The findings indicated that patients found the internet to be a complementary information source alongside healthcare professionals. Healthcare professionals were perceived to be the most reliable and valued information source. The most common reason to use online health forums was to plug information gaps surrounding diagnosis or treatments. Forums were used to aid decision-making such as whether to seek further medical attention, and to source information on lifestyle choices, medications and other advice. Forum responses were analysed for diagnostic accuracy and only a small minority were found to be evidence based. Signposting to other sources and responses containing unsubstantiated advice were far more common. The interview study found similarities and differences in public and healthcare professional perceptions. Healthcare professionals had hesitancies and were cautious of patient’s using the internet for health information but were in favour of patients becoming more knowledgeable and working together to make informed decisions. Likewise, public participants searched online to understand information gained from their healthcare professional and hoped to work in a professional partnership and become more involved in the decision-making process.

Conclusion and Implications: Rather than online health information seeking inevitably undermining the patient-healthcare professional relationship, using a broad and triangulated research design, this study provides evidence that potentially beneficial outcomes may result from this growing phenomenon. The research offers insights into peer-focused resources such as online health forums and the perceptions of the public and healthcare professionals. Recommendations relate to the adapting of behavioural and communicative approaches appropriate for internet-informed patients. The nursing profession should recognise the significance of the phenomenon and incorporate it into education and development programmes.

Table of contents

List of Figures

List of Tables

Acknowledgements

I would like to thank my primary supervisor Professor Bridget Johnston, for being such a committed and inspiring mentor. Without Bridget's continuous source of support, encouragement and expertise, this PhD would not have been possible. I would also like to thank my second supervisor Professor Frances Mair, for providing continuous commitment and patience throughout my PhD, and for invaluable expert knowledge and support.

To both Professor Bridget Johnston and Professor Frances Mair, thank you for being a wonderful supervisory team. I will miss leaving every meeting full of inspiration and motivation. Thank you for making my PhD such an enjoyable journey.

I would like to thank my PPI participants, Beverley and Tommy. Their experiences helped shape this thesis and I appreciate the time they have both put in to meeting me and sharing their thoughts on my research. Additionally, thank you to all participants that took part in this research, who willingly and generously offered their experiences to help form the findings of this PhD thesis.

Thank you to my PhD colleagues who made the office such an enjoyable place to study, and who have provided friendship and support over the years.

Finally, I am indebted to my family and friends for their support. A special thank you to my dad, who has given me belief and hope in everything I have done throughout this PhD and daily life and has been a continuous inspiration. To my mum, whose love and support has been the drive to get me here and always kept me going. My gran, for being one of the reasons I became a nurse, and always inspiring me with her strength. To my brothers and sister, who have asked me every day when I will be finishing my PhD, I made it!

I am truly grateful to everyone who has supported me through this journey, thank you for everything.

Author’s declaration

I declare, that except where explicit reference is made to the contribution of others, this PhD thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institutions.

Printed name: Annabel Farnood

List of publications/dissemination of research

The following is a list of my publications and conference presentations resulting from the work in this thesis:

Publications arising from this PhD study

- **Paper 1 (Chapter 5):** A mixed methods systematic review on the effects of patient online self-diagnosis, on the patient-healthcare professional relationship – **published in the BMC Medical Informatics and Decision-Making journal.**

  (Farnood, A., Johnston, B. & Mair, F.S. A mixed methods systematic review of the effects of patient online self-diagnosing in the 'smart-phone society' on the healthcare professional-patient relationship and medical authority. BMC Med Inform Decis Mak 20, 253 (2020). https://doi.org/10.1186/s12911-020-01243-6.)

- **Paper 2 (Chapter 6 – phase 1):** Understanding the use of heart failure online health forums: a qualitative study – **published in the European Journal of Cardiovascular Nursing.**

  (Farnood, A., Johnston, B., & Mair, F.S. (2021). Understanding the use of heart failure online health forums: a qualitative study. European Journal of Cardiovascular Nursing. https://doi.org/10.1093/eurjcn/zvab090.)

- **Paper 3 (Chapter 6 – phase 2):** An analysis of the diagnostic accuracy and peer-to-peer health information provided on online health forums for heart failure – **published in the Journal of Advanced Nursing.**

  (Farnood, A., Johnston, B., & Mair, F.S. (2021). An analysis of the diagnostic accuracy and peer-to-peer health information provided on online health forums for heart failure. Journal of Advanced Nursing, 00, 1-14. https://doi.org/10.1111/jan.15009.)

Conference presentations arising from this PhD study

- Poster presentation at the **School of Medicine, Dentistry and Nursing Postgraduate Research Day**, University of Glasgow (2021) - *An Analysis of the Diagnostic Accuracy and Peer-to-Peer Health Information Provided on Online Health Forums for Heart Failure.*

- Poster presentation at the **European Association for Palliative Care conference** (digital conference - 2020) - *An understanding the use of heart failure online health forums: a qualitative study.*

- Poster presentation at the **European Association for Palliative Care conference** (digital conference - 2020) - *mixed methods systematic review on the effects of patient online self-diagnosis and health information, on the patient-healthcare professional relationship.*

- Presented my PhD thesis in the University of Glasgow **3MT competition** (2020) – **Heat Winner.**

- Invited for an oral presentation in a 3MT format - presenting my PhD thesis at the **Life Underwriting, Claims and Insurance Doctors (LUCID) conference** in Glasgow (2019).

- Poster presentation at **the U21 Health Sciences Annual Meeting** at the University of Glasgow (2019) - *mixed methods systematic review on the effects of online self-diagnosis and health information, on the patient-healthcare professional relationship.*

- Oral presentation at the **Royal College of Nursing (RCN) International conference** at the University of Sheffield (2019) - *mixed methods systematic review on the effects of online self-diagnosis and health information, on the patient-healthcare professional relationship.*

- Oral presentation at the **Society for Academic Primary Care (SAPC) conference** at the University of Exeter (2019) **-** *mixed methods systematic review on the effects of online self-diagnosis and health information, on the patient-healthcare professional relationship* – **winner of the early career research prize.**

- Presented my PhD thesis in the **3 Minute Thesis (3MT) competition** at the Institute of Health and Wellbeing Research Away Day (2018) – **Prize Winner.**

Abbreviations

Abbreviation	Description
AACODS	Accuracy, Authority, Coverage, Objectivity, Date, Significance
BHF	British Heart Foundation
CAQDAS	Computer-Assisted Qualitative Data Analysis Software
COREQ	The Consolidated Criteria for Reporting Qualitative Research
ECG	Electrocardiogram
GP	General Practitioner
HCP	Healthcare Professional
NICE	National Institute for Health and Care Excellence
NPT	Normalization Process Theory (American spelling will be used as this is used by the authors and on the website).
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
SIGN	Scottish Intercollegiate Guide Network
UK	United Kingdom
US	United States
WHO	World Health Organisation

Chapter 1 - Introduction

1.1 Introduction

This thesis and the research presented therein, examines the growing phenomenon of online health information seeking and the effect this may be having on the relationship between patients and healthcare professionals (nurses, doctors and allied healthcare professionals, hereafter 'HCPs'). The aim of this introductory chapter is to explain the motivation for the study, describe the research topic and state the research problem which originally prompted the research to take place. In the course of this, a set of research objectives and a set of research questions that will guide and delimit the thesis will be presented. At the end of this chapter, there is an outline of how the chapters of this thesis are organised.

The motivation to investigate this particular research topic came from both being in the nursing profession and from personal experiences. During the course of my master's degree in Advanced Nursing Practice, I began to reflect on the role of socio-demographic factors influencing the health of the people of Glasgow. Comments regarding acquired online health information made by patients during my nursing practice suggested that the recent emergence of access to medical information was feeding through into the patient-HCP relationship. I began to formulate ideas for research which would help understand the potential role of online health information seeking and whether this was set to become a socio-demographic factor of the future. I started asking other HCPs in my social network if they had noticed online self-diagnosis giving rise to changes in behaviour and in the nature of the relationship between themselves and patients. I found that colleagues had much to say on the matter suggesting that it was emerging as a significant issue. After reviewing the current literature on the topic, I decided that this phenomenon merited research and was one that I felt passionate about undertaking.

One phase of the research examines online health forums related to heart failure. My interest in heart failure stems not only from the large gaps in research within this topic area, but also from a personal interest. My grandmother was diagnosed with heart failure after a complex cardiac history, and she has given me inspiration to explore the concept of heart failure online health information and make a contribution to research through a nursing lens. I have been involved in my grandmother's care and, due to this, I have an understanding of the importance of gathering views from a HCP perspective and a patient/public/carer or relative perspective. Having lived these experiences myself, I found this to be a subject matter of importance and one I could embark upon.

1.2 Research problem

In the traditional patient-HCP relationship, the HCP was always the diagnostic advisor (Townsend et al., 2015). However, in the present day with burgeoning volumes of health information of varying quality appearing on the internet and through mobile applications, this role may be changing as the knowledgeable patient increasingly develops as a result of growing information accessibility (Qudah & Luetsch, 2019).

Fifteen years ago, there were signs that the paternalistic perception of the doctor-patient relationship was beginning to lessen globally (Pincock, 2003). This was prior to the boom in internet connectivity and mobile computing and the great increase in health-related content available online. However, another dimension is that the health information that can be found in such large quantities, is also of greatly variable quality, ranging from peer reviewed journal articles to patient anecdotes in forum posts (Tustin, 2010).

Recent years have seen health information seeking grow rapidly. By 2013, a nationwide telephone survey reported that more than one-third of US adults were already turning to the internet for medical information for diagnosis purposes (Fox & Duggan, 2013). In the UK, a GP survey reported that three-quarters of GP's had noticed an increase in patients self-diagnosing online and 21% had experienced patients presenting with the information they found online (McArdle, 2015). The main concern reported by GPs in this survey was that such online self-diagnoses would lead to increased appointment-making by the 'worried well'.

While a body of empirical evidence has yet to be produced, it is clear that the increasing use of online health information by patients and the public, may be having an effect on the patient-HCP relationship, and is worthy of investigation. The patient-HCP relationship has been described as "one of the essential axes of the optimal clinical care" (Banos Diez, 2007), so understanding the influences of the increasing use of online information resources on this relationship is an important research endeavour.

1.3 The research context

The relative newness of access to medical information online, particularly on smartphones in the form of downloaded apps, means that there is only a small amount of empirical work on the phenomenon, though interest is undoubtedly growing. It is important to understand whether patient empowerment and engagement through access to effectively the same knowledge bank as nurses and HCPs, bring positive benefits or undermine this relationship.

More of the world's population has access to the internet than are without it and in some countries such as the United Kingdom and the United States, more than nine out of ten people are connected (Internet World Stats, 2018). The 'global village' that McLuhan (1964) predicted in the 1960s, had 4.15 billion citizens at the end of 2017 compared with 1.6 billion just ten years earlier (Internet World Stats, 2018). This period has also been characterised as that of Web 2.0. This concept signalled a change in the internet from a place for publishing to a place to participate and interact. One highly significant aspect of Web 2.0 for the questions being addressed in the present study, is that a key characteristic of the new internet was that anyone can contribute. Instead of the publishing of health information being restricted to website owners, now users could have their own text published. As Lo and Parham (2010) explained,

> Organisations that set up websites no longer solely control the content of information on the site, nor is content produced only by experts and traditional publishers. Users now contribute to the information on a website with the advent and proliferation of chat rooms, wikis, blogs, and comment sections (p.19).

Furthermore, Web 2.0 search engines, most notably Google, are frequently the starting point for health information seeking and the results they present to the user may be filtered for relevance but not necessarily for quality. Searches for common symptoms return tens of millions of search results (Keselman et al., 2008).

The devices used to access information and interact, have also undergone sweeping change. Instead of the desktop computer dominating, first laptops then tablets and smartphones, became commonplace. Survey research from 2012-2021 reported that smartphone ownership in the UK reached 92% in 2021. In 2016, less than half of respondents over the age of 55 owned a smartphone device, and in 2021 it rose to 83% (Statista, 2021).

Additionally, with the 55% of people with a tablet computer in their household (Statista, 2021), it is clear that not only is the global village connected but it is connected through multiple devices. Through these devices, our information rich societies can access almost 1.8 billion websites, though ‘only’ around 200 million of these are active (Internet Live Stats, 2018). The question of how many of these sites publish health-related information is difficult to say with accuracy, because health information can be published and sought in places that are not ostensibly health related, Facebook would be a good example (Procter, 2021).

The rise of mobile computing raised the prospect of patients accessing information about their symptoms, which could occur on the way to an appointment or in the waiting room - the information could even be taken into the consultation or on the ward (Snyder et al., 2011). Hence the phenomenon of health information seeking is not a remote unseen activity or background noise, but a direct and personal feature of the one-to-one relationship between patients and HCPs. The transparency of, and access to medical knowledge has been increasingly matched by health consumerism manifesting itself online in the form of reviews and ratings whereby individual ‘consumers’ posted their evaluation of healthcare providers, particularly in the United States. The NHS itself publishes this kind of content as part of its ‘your choices’ approach (NHS, 2019; Department of Health and Social Care, 2020).

Another phenomenon that accompanied these technological trends was the rise of health consumerism and the participative relationship between HCP and ‘consumer’ which, in some societies more than others, was replacing the more directive and paternalistic approach that had existed for decades (Muir Gray, 2002). This change in the relationship may have fuelled the demand for online health information or it may have been caused by the proliferation of such information. In 1998, when American health information provider, National Library of Medicine, made Medline available to the public online, its website traffic skyrocketed from seven million searches in 1997 to 120 million the following year, demonstrating the pent-up demand for health information among the general public (Cline & Haynes, 2001).

While older people may have continued to view HCPs as figures of authority and not to be questioned, an increasing proportion of the population were growing up with a different mindset. Prensky (2001) argued that the younger generation had fundamentally changed the way they now think and process information due to having grown up with new technology

(Prensky, 2001). These ‘digital natives’ were contrasted with those who tried to adapt to the new technology with varying degrees of success as ‘digital immigrants’.

Research on internet health information seeking has evolved over time as internet capabilities have advanced and accessibility to the internet has widened. In the 1990s, research focused on internet access and the ‘digital divide’ between those with computer access and those who did not (Pew, 2013). Research then began on the credibility of health information found online (Eastin, 2001; Eysenbach & Kohler, 2002; Bodie & Dutta, 2008; Sarkar et al., 2010).

Although accessibility to computers and technology has extensively increased, the ability to use them efficiently has been slow to develop (Boot & Meijman, 2010). The increasing availability of technology coincides with a growing number of people who report difficulty in finding relevant information on the internet. Therefore, the factors that shape success in finding reliable online health information, have become increasingly important.

Concerns have been raised from within the nursing profession that some of the information being accessed by patients may be of poor quality, and instead of being based on robust clinical evidence, are merely representing commercial interests (Warner, 2011). Clearly, nurses are a group of HCPs for whom the phenomenon of online self-diagnosis is important, leading to obligations and potential responsibilities in terms of educating the public in its use. No UK empirical studies on this topic which have explored nurse’s perceptions of patient self-diagnosis and online health information, have been located. Online health information seeking as an academic research field has grown in tandem with the rise in internet connectivity and the large volumes of information available over the internet (Zhao & Zang, 2017; Brown et al., 2020; Procter, 2021).

1.4 Scope and terms of the research

1.4.1 Scope of the research

Geographically this study does not set limitations as online information seeking is not confined by national borders. The literature cited in this thesis comes from many different countries. Additionally, in terms of primary data, the subjects in the present study are all located globally.

Temporally the research is interested in the last decade as this is the period in which Web 2.0 has established itself, smartphones have proliferated, and high-speed connectivity has spread to many parts of the globe. The potential for an effect on the patient-HCP relationship from online health information seeking had been recognised before this, but the developments discussed in this chapter show that it is in the last ten years that the issue has escalated both as a social phenomenon and as an area of academic inquiry.

The patient behaviours of interest are broad in that there are many types of health information available and many ways it could be used, from self-diagnosis, evaluating treatment options to preparing for medical appointments. They also include reading and contributing to online health forums. Participation in online health forums is of interest in the present study due to the opportunity of health information exchange from a patient perspective.

1.4.2 Terms of the research

1.4.2.1 Defining online self-diagnosis and health information seeking

At present, the literature regarding the concept of health information seeking does not provide a dominant definition. Unlike clinical studies which adhere to a strict set of universally used terms for conditions and interventions, the way this behaviour is named varies with ‘online’, ‘internet’, ‘electronic’ and ‘worldwide web’, all featuring in the literature. Therefore, after careful analysis, the two terms used to describe this study were online self-diagnosis and online health information seeking. These two definitions brought the most relevance to the aims of this study, as the goal was to understand motivations underpinning online self-diagnosis, and behaviours of online health information seeking.

Online self-diagnosis refers to people engaging with technology by applying their own knowledge and skills to generate medical diagnoses themselves, without the participation of a HCP (Hu & Haake, 2010; Kuehn, 2013). Online health information seeking is an umbrella term for factors that lead to information seeking (Caiata-Zufferey et al., 2010). As described above, there is a lack of definition for online health information seeking. However, there are some shared characteristics which include skills to gather information, information processing, and understanding the obtained health information to make suitable health decisions.

For the purpose of this study, health information seeking is defined as,

> …verbal and nonverbal messages ascertained via everyday interaction, either purposeful or serendipitous, by members in a self-defined network, that serve not only to reduce uncertainty regarding health status, but also to construct a social and personal (cognitive) sense of health (Tardy & Hale, 1998, p. 338).

1.4.2.2 Defining healthcare professionals

Within this thesis, the abbreviation 'HCP', is used frequently, so it is important to define HCPs in terms of the thesis subject. This research will predominantly focus on the nurse and doctor roles. Historically, the doctor has had a dominant role in diagnostic practice. However, this research will emphasise the expanding role of the nursing profession and how this research problem will be increasingly important to future nursing practice. As technology continues to develop, it will continue to contribute and affect the way people perceive their healthcare. It is important to establish this research in a field where nurses have not been the dominant focus, and to have research that will contribute towards nursing practice and research with regard to internet informed patients and the phenomenon of online self-diagnosis and health information seeking.

To successfully conduct this research, it is essential to include the role of the doctor, where research has been more established. Scoping previous literature, gaining doctor's perceptions and understanding the impact on the patient-HCP relationship, will prove effective and important for developing recommendations for HCPs with internet-informed patients. This research will predominantly use the term 'HCP' with regard to nurses and doctors. However, it is important to also consider other allied HCPs such as physiotherapists, as they also contribute to patient care and provide diagnostic advice.

1.5 Research objectives and questions

1.5.1 Research objectives

- To add to understanding of how patient online health information seeking affects the patient-healthcare professional relationship and medical authority.
- To examine the range of health information available to patients online and its quality, particularly heart failure.
- To review what is known about patients' online health information seeking behaviour.
- To analyse nurses and other healthcare professional's perceptions of patient online health information seeking behaviour and its effect on the patient-healthcare professional (nurses, doctors and other allied healthcare professionals) relationship.
- To explore patients' interpretations of their online health information seeking behaviour and its effect on the patient-healthcare professional relationship.
- To explore the impact and interpretation of COVID-19 online health information.
- To present practical recommendations to healthcare professionals, healthcare professional representative organisations, healthcare managers, public health authorities, publishers of online medical information and patients/public (taken together as stakeholders) regarding the effect of patient online health information seeking behaviour on the patient-healthcare professional relationship and medical authority.

1.5.2 Research Questions

Each research objective can be translated into a research question. Ten research questions are set for the present study with the first (RQ1) being the main overarching question and the remaining nine each addressed through particular chapters in the thesis.

RQ1 - Overall aim. How does online health information seeking affect the patient-healthcare professional relationship and medical authority?

RQ2. How do healthcare professional's perceive patients use of online health information and its effect on the patient-healthcare professional relationship?

RQ3. How do public/patients perceive the use of online health information and its effect on the patient-healthcare professional relationship?

RQ4. How does online health information seeking shape people's decision-making?

RQ5. What information do people concerned about heart failure seek when using online health forums for self-diagnosis?

RQ6. How does the use of online health forums, in the context of heart failure, affect people's trust in healthcare professionals?

RQ7. How evidence based is the diagnostic advice provided on heart failure online health forums and what are the types of information responses provided on them?

RQ8. What are the public and healthcare professional perceptions of online health forums and social media support groups as an information source?

RQ9. How has the availability of online health information influenced the patient-healthcare professional relationship?

RQ10. What are the perceptions of online health information surrounding COVID-19 and the impact of such information sources among healthcare services?

(The COVID-19 research objective and RQ10 was additionally included to this PhD study as the COVID-19 pandemic emerged during the course of this PhD).

1.6 Structure of the thesis

The thesis is structured to systematically achieve the research objectives and address associated research questions in specific chapters of the thesis, as shown in Table 1-1.

Table 1-1: The structure of the thesis

Research Objective	Research Question	Chapter question addressed
1). To add to understanding of how patient online information seeking affects the patient-HCP relationship and medical authority.	**RQ1 - Overall aim.** How does online health information seeking affect the patient-HCP relationship and medical authority?	**All chapters**
2). To examine the range of health information available to patients online and its quality, particularly heart failure.	**RQ5.** What information do people concerned about heart failure seek when using online health forums for self-diagnosis? **RQ6.** How does the use of online health forums, in the context of heart failure, affect people's trust in HCP's? **RQ7.** How evidence based is the diagnostic advice provided from heart failure online health forums and what are the types of information responses provided on them? **RQ8.** What are the public and HCP perceptions of online health forums and	**Chapter Two:** Literature Review **Chapter Six**: Findings: Heart Failure Online Health Forums **Chapter Eight:** Discussion

	social media support groups as an information source?	
3). To review what is known about patients' online health information seeking behaviour.	**RQ3.** How do public/patients perceive the use of online health information and its effect on the patient-HCP relationship? **RQ4.** How does online health information seeking shape people's decision-making?	**Chapter Two**: Literature Review **Chapter Five:** Mixed Methods Systematic Review **Chapter Six:** Findings: Heart Failure Online Health Forums **Chapter Eight:** Discussion
4). To analyse nurses and other healthcare professional's perceptions of patient online health information seeking behaviour and its effect on the patient-healthcare professional (nurses, doctors and other allied healthcare professional's) relationship.	**RQ2.** How do HCP's perceive patients use of online health information and its effect on the patient-HCP relationship? **RQ9.** How has the availability of online health information changed the patient-HCP relationship?	**Chapter Five:** Mixed Methods Systematic Review **Chapter Seven**: HCP perceptions of patient online health information seeking **Chapter Eight:** Discussion
5). To explore patients' interpretations of their online health information-seeking behaviour and its effect on the patient-HCP relationship.	**RQ3.** How do public/patients perceive the use of online health information and its effect on the patient-HCP relationship?	**Chapter Five:** Mixed Method Systematic review **Chapter Seven**: Patient Perceptions of online health information seeking

	RQ9. How has the availability of online health information influenced the patient-HCP relationship?	**Chapter Eight:** Discussion
6). To explore the impact and interpretation of COVID-19 online health information.	**RQ10.** What are the perceptions of online health information surrounding COVID-19 and the impact of such information among healthcare services?	**Chapter Seven:** Patient and HCP perceptions of patient online health information seeking **Chapter Eight:** Discussion
7). To present practical recommendations to stakeholders regarding the effect of patient online health information seeking behaviour on the patient-HCP relationship and medical authority.	**All questions.**	**Chapters Eight and Nine:** Discussion and conclusions of the research

1.6.1 Chapter summaries

Chapter One outlines the research problem, presents the context of the research and then describes its scope and key terms. After this the objectives and research questions are presented. Finally, the way the thesis is organised, is explained chapter by chapter.

Chapter Two presents the existing evidence base regarding online self-diagnosis and health information seeking in the wider concept of healthcare. Health information behaviours are examined through the literature and consideration given to what is already known about the patient-HCP relationship, in the context of online health information seeking.

Chapter Three describes the approach to knowledge and the reasoning underpinning the methodological choices made. The adoption of a critical realist paradigm is justified.

Chapter Four outlines the research methods employed for each phase of the research and discusses the rationale for the chosen approaches. The steps the researcher took to operationalise each phase of the research are set out with appropriate detail.

Chapter Five (phase 1) presents a systematic review of both qualitative and quantitative studies addressing the effects of patient online self-diagnosing in the 'smart-phone society' on the patient-HCP relationship and medical authority.

Chapter Six (phase 2: parts 1 and 2) presents the findings of phase 2 of the research. The first part comprises the examination of heart failure online health forum posts and the second, the responses to these posts. The quality of responses in clinical terms is analysed.

Chapter Seven (phase 3) presents the findings of the interview study in which both the public and HCP's perceptions of the phenomenon of online health information seeking and its effect on the patient-healthcare relationship are investigated.

Chapter Eight synthesises the findings of each phase of the research and discusses them both in the context of the existing knowledge base and in the light of the research questions presented in Chapter One.

Chapter Nine proposes the main conclusions of the study, its empirical, theoretical and methodological contributions and the implications for research, practice and policy. Final thoughts on the research journey are also offered.

Chapter 2 - Background to the research topic

2.1 Introduction

The aim of this chapter is to present the evidence base regarding online self-diagnosis and health information seeking in the wider concept of healthcare. This chapter sets the scene for the study by exploring the concept of health information seeking behaviour and reviewing existing studies. Secondly, some of the key contextual and personal factors influencing health information seeking as a response to illness, and an integral part of help-seeking and illness behaviour are explored. Active information seeking and passive receipt of information processing will be explored by looking at health information behaviours and, afterwards, the relationships with patients/public and HCPs in regard to online health information seeking will be examined. The patient/public outcomes from online health information seeking will be reviewed, looking at patient empowerment and satisfaction. Finally, gaps in the evidence base regarding heart failure and online health information seeking are highlighted.

2.2 Eligibility criteria for reviewing the literature

Studies for this review were evaluated based upon eligibility criteria. For an article to be selected, it had to focus on one or more of the following five topics: (1) patient/public use of the internet for online self-diagnosis or health information seeking, (2) patient/public health information seeking behaviours, (3) the impact of online health information seeking behaviour on the patient-HCP relationship, (4) the use of online health forums, and (5) searching for heart failure online health information.

To maintain the focus on patient/public use of the internet for health information, the following exclusion criteria were employed. Articles were excluded if they: (1) described HCP and student HCP use of the internet for health information, (2) discussed paediatric health/parents searching for children, (3) included pharmaceutical companies searching for medications, (4) were otherwise not relevant to the focused topic.

The literature search was limited to studies from the years April 2007 to April 2021. This 14-year parameter was placed on the literature as 2007 was a landmark year with the launch of the first Apple iPhone (Apple, 2007). The search was further refined by limiting it to literature only in the English language and articles with the title of online health information/self-diagnosis/seeking. All peer reviewed study types were included, and a grey literature search was undertaken. Papers were reviewed in terms of their potential contribution in understanding of online self-diagnosis and health information seeking.

2.3 Data sources

The goal was to capture a comprehensive overview across the diverse literature on online health information seeking and self-diagnosis. The database search included the following databases: CINAHL, MEDLINE, EMBASE and PsycInfo (Table 2-1).

For the database searches, terms were combined in multiple ways using Boolean operators, (AND, OR). Truncation (a word that could have multiple headings) and wild carding (an advanced search technique that can be enabled to maximise search results) were used when available (North Central University Library, 2021). Terms were modified to reflect the organisation of the database used. Keywords for literature searching were identified from the study aims and articles accessed in the early stages of the review are presented in Table 2-2.

To achieve a comprehensive literature review, grey literature is an important element to include. Grey literature searches are generally not as systematic as traditional methods of systematic searches for academic literature. One definition of this type of literature states,

> Grey literature is a field in library and information science that deals with the production, distribution, and access to multiple document types produced on all levels of government, academics, business, and organisation in electronic and print formats not controlled by commercial publishing, i.e., where publishing is not the primary activity of the producing body (Grey Net International, 2020).

Accessing material published on the internet can have complexities due to the extensive amount of information and lack of standard indexing (Pappas and Williams, 2011). There is no 'gold standard' for rigorous systematic grey literature search methods (Bickley et al., 2020). However, prior to conducting the grey literature search, a search plan was outlined. Google and Google Scholar were both searched, and the literature was evaluated using the 'AACODS' checklist, designed by Flinders University, South Australia, to help evaluate grey literature (authority, accuracy, coverage, objectivity, date, significance) (Flinders University, 2010).

Keywords used in the grey literature search included ‘online self-diagnosis’, ‘online health information’, ‘online health information seeking’, online health forums’, ‘heart failure’ and ‘patient-HCP relationship’. The key terms were entered into the advanced search tool of Google where it narrowed the search to only English literature and published from 2007 onwards. The search term (“online self-diagnosis” OR “online health information” AND “heart failure”) or (“online self-diagnosis” OR “online health information” AND “patient-healthcare professional relationship”) was used on Google and Google Scholar when undertaking searches. In some instances, document searches resulted in thousands of hits. In such cases, the first 100 links were searched as typically, the first two pages of google search results are most browsed by the internet user (Jacobson, 2015) therefore this method was adopted for this search.

Table 2-1 lists resources searched and their subject area coverage. Search terms are shown in Table 2-2.

Table 2-1: Resources searched

Bibliographic databases	**Coverage**
Medline	Medical and biomedicine
CINAHL	Nursing and allied health literature
EMBASE	Covers all of Medline with the inclusion of drug and pharmacy journals
PsycINFO	Psychology literature
Internet based publications www.google.com search engine Google Scholar	General searches Scholarly literature

Table 2-2: Search terms

Topic	**Keywords**	**Databases**
Method of seeking information	Self-diagnosis or information seeking	MEDLINE, CINAHL, EMBASE, PsycInfo
The internet as an information source	Online or internet	MEDLINE, CINAHL, EMBASE, PsycInfo
People using the internet	Patient* or public	MEDLINE, CINAHL, EMBASE, PsycInfo
The effects on the patient-HCP relationship	The patient-physician relationship	MEDLINE, CINAHL, EMBASE, PsycInfo
Heart failure	Heart failure or congestive heart failure	MEDLINE, CINAHL, EMBASE

The number of retrieved results from the database searches are presented in Table 2-3. The first eligibility review applied the exclusion criteria to titles and abstracts, resulting in 77 articles. Next, full-text articles were reviewed, and exclusion criteria applied. In total 38 articles met all the above criteria and so were included in this literature review.

The grey literature Google search yielded a total of 237 results. Google Scholar yielded thousands of results therefore, only the first 100 were only scanned for eligibility. In total from the grey literature search, a total of 9 were retained after applying the eligibility criteria.

Table 2-3 Number of retrieved results from database search

MEDLINE (Ovid)	**CINAHL**	**EMBASE**	**PsycInfo**	**Grey literature**	**TOTAL**	**De-duplication:**
109	72	151	311	237	880	586
						Final number of included articles:
						47

2.4 Framework for the literature review

It has been suggested that a literature review be conceptualised within a theoretical framework (Marshall & Rossman, 2014). The framework used for structuring this literature review is Longo’s expanded model of health information seeking behaviours (Longo, 2005) (see Figure 2-1).

Longo’s model is designed to help understand the nature and usage of health information related to chronic disease (Longo, 2005). Longo et al. designed this model in 2005 to explore the information seeking behaviour of women with breast cancer (Longo, 2005). The authors applied the same model to investigate the information seeking behaviour of diabetic patients and created a new model which expanded the original one (Longo et al., 2010).

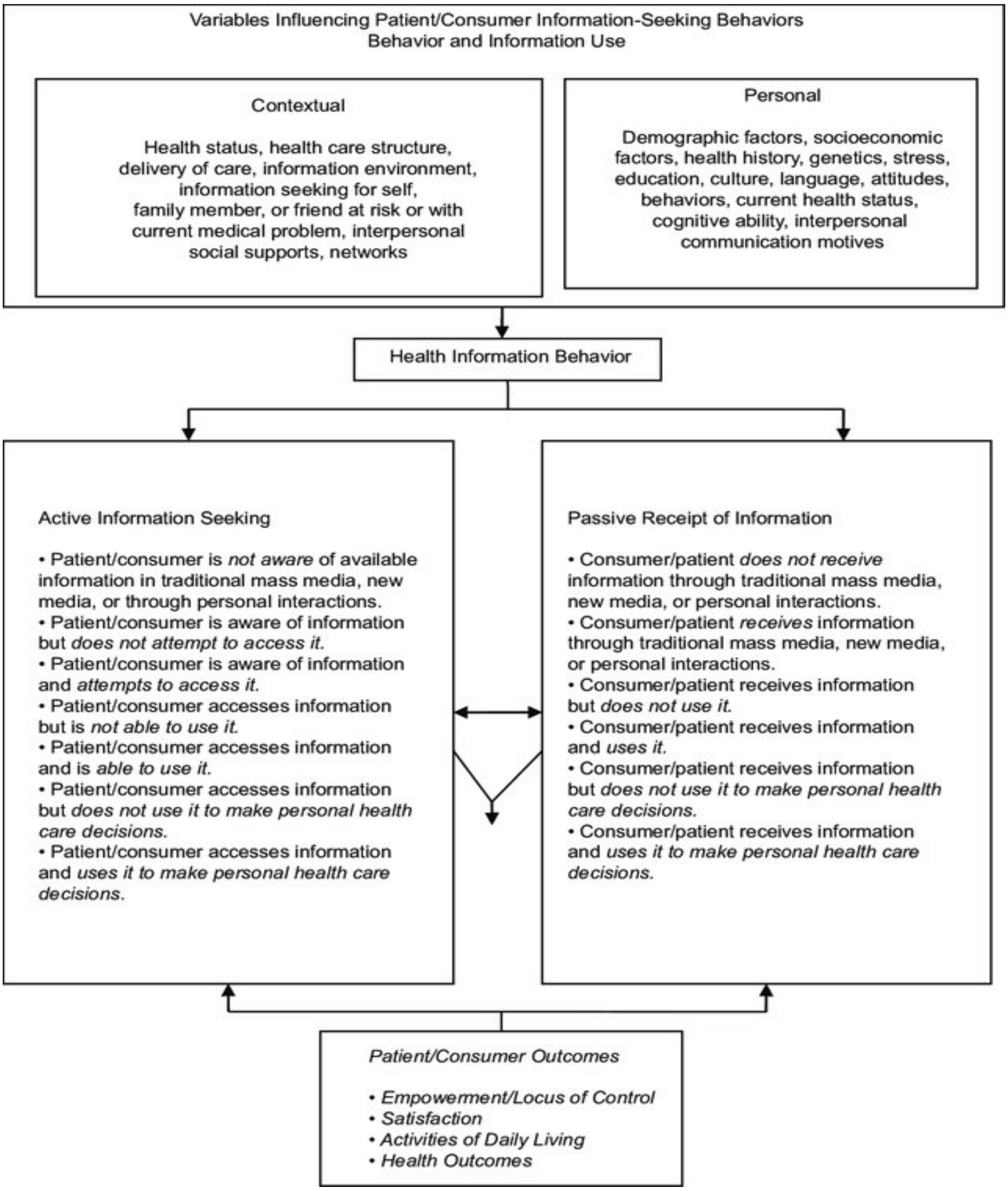


Figure 2-1: Longo’s expanded model of health information seeking behaviours (based on Longo, 2005).

The model consists of personal and contextual factors and include both active information seeking and passive receipt of information as information seeking behaviours, as presented in Figure 2-1 (Longo, 2005). Applying the model to the present study will help identify key factors influencing health information seeking among the literature.

2.5 Contextual factors impacting online health information seeking

It is evident that many components shape health information seeking. These contextual factors assimilate the information seeking context and the source of the information. Contextual factors such as health literacy, availability of support networks, information reliance, health status and motivations all play a role in health information seeking behaviour. Contextual factors related to online health information seeking are now discussed as a series of subthemes.

2.5.1 The prevalence of online health information seeking

Online health information seeking and self-diagnosis is a growing global phenomenon (Snyder et al., 2011) with the internet being the fastest growing platform for health information and the largest medical library in the world (Graffigna et al., 2017). Due to technological advances, the internet is more accessible than ever, with usage continuing to increase (Perrin & Duggan, 2015).

The internet provides a platform for people that allows information to be presented in different formats such as graphics, audio, or text; it has up-to-date health information and provides support for health-related problems (Chung, 2014; Plinsinga et al., 2019). One study discussed the online health information seeking behaviour of 1142 patients hospitalised with acute coronary syndrome (Waring et al., 2018) and found that more than half of the patients had used the internet to seek health information four weeks before being admitted. Additionally, patients who were hospitalised with an acute myocardial infarction, had impaired health numeracy or a lack of social support networks, were less likely to report their online health information seeking (Waring et al., 2018).

The rising use of smartphones (Carbonell et al., 2018) and rapidly increasing availability of health information on the internet, has led to more people using the internet as their first healthcare resource, often before seeking professional advice (Gualtieri et al., 2009). Consequently, there is growing interest in the effect of these changes in behaviour on health outcomes as well as the potential impact on the patient and HCP relationship.

2.5.2 Motivators for accessing online health information (seeking for self)

Motivators for accessing online health information are varied. Lambert and Loiselle (2007) suggest three main reasons: preventative health; illness management; and involvement in medicinal decisions. The benefits of availability and accessibility of online health information allows people to become more informed and provides methods to become more engaged in their own healthcare (Jeong et al., 2018).

Boot and Mejiman (2010) conducted a systematic literature review to understand people's drives for using the internet to seek health information. They concluded five central drivers which contribute to seeking health information: knowledge drivers (searching to build knowledge); social drivers (searching to find solidarity); uncertainty drivers (searching due to uncertainty and fear); entertainment drivers (searching for entertainment purposes); self-actualisation drivers (searching to improve self-esteem and achieve the best possible health status) (Boot & Mejiman, 2010). Although, these five drivers do not account for all reasons for seeking health information, they are among the factors to consider when understanding people's information seeking motives. An online survey by Chung (2014) posits that wanting to learn more about one's health condition, further information about treatment of conditions, and advice from other peers who are sharing similar experiences, are leading motivators.

Findings from the World Health Organisation (WHO) eHealth survey, indicated that 29% of people who accessed health information online, used it to determine whether they should visit their HCP (Sorenson et al., 2008). Literature discussed the timing of use of the internet for accessing online health information, finding that it was most common before and/or after an appointment with a HCP (Bell et al., 2011; Boot & Mejiman, 2010; Caiata-Zufferey et al., 2010; Tan & Goonawardene, 2017).

Commonly reported reasons for people visiting the internet before a consultation included the desire to identify the HCP they will consult with, preparing so they can communicate their health concerns effectively (Caiata-Zufferey et al., 2010; Tan & Goonawardene, 2017; Farnood et al, 2020) and to understand medical jargon better (Tan and Goonawardene, 2017). Furthermore, people who searched prior to the appointment, felt more comfortable with the HCP's advice (Tan & Goonawardene, 2017). Reasons reported for people visiting the internet after a HCP appointment was due to curiosity (Bell et al., 2011; Boot & Mejiman, 2010) and the HCP providing too little information (Bell et al., 2011; Caiata-Zufferey et al., 2010; Haluza et al., 2017; Litzkendorf et al., 2020). Further predictors of online health information seeking post appointment were due to mistrust and worrying (Bell et al., 2011).

2.5.3 Surrogate seekers (seeking for others)

Health information seekers are mostly looking for interpretation of disease or information on their condition in order to discuss their situation in-depth with their HCP. Additionally, online health information seekers not only search for their own health-related problems, but also for their relatives or loved ones (Waring et al., 2018). Nolke et al. (2015) cross-sectional survey found that one third of their respondents from a total of 2000 participants, search for health information for another person who is unwell. In a secondary analysis study looking at cross-sectional data from the Pew Internet and American Life Project, the difference between self-seekers and those who additionally act as surrogate seekers (seeking for others) was investigated (Sadasivam et al., 2013). Surrogate seekers were most commonly both married and a parent, or of excellent health status, a caregiver of an adult relative, or have someone close to them with a serious medical condition or chronic illness. However, the findings suggest the information seeking needs of some surrogate seekers, particularly caregivers, are not being met (Sadasivam et al., 2013).

Caregivers have reported difficulties in caring for their loved ones which can include psychological and emotional challenges, as reported in a survey study about dementia patients' caregivers (Jeong et al., 2018). However, the internet offered caregivers a platform to search and exchange informal information online through information sharing, to help cope with such challenges (Jeong et al., 2018).

2.5.4 Heart failure and heart conditions

Several studies have assessed the readability of disease-related and medical procedure-related information online, however, Cajita et al. (2017) was the only study to appear within this search that discussed heart failure health information within the context of online health information seeking. The authors evaluated the quality of and health literacy demand for heart failure information found online from 46 websites and concluded that it was of fair quality but required a relatively high level of health literacy. Additionally, it was found that the readability level of heart failure websites was much higher than the recommended readability grade. This suggests potential for misinformation that may lead to further appointment booking or use of other sources such as heart failure online health forums.

2.5.5 Informal social support networks

The influence of an individual's social network is linked to illness behaviour with online health information seeking being structured as a result of such networks (Willis, 2014). Social networks can include relatives, friends or online networks, and can influence all stages of the help-seeking process from symptom perception, illness experience, lay referral system and health service utilisation (Boot & Mejiman, 2010; Johnston et al., 2013). It is common to seek advice from informal sources when trying to make sense of symptoms and decide upon actions that need taking. Chung (2014) reported that the number of people using social media for health reasons is expected to increase. Furthermore, social media such as online support groups, patient blogs and health related social networking sites have materialised into popular sources of health information.

People with limited social support networks were less likely to use the internet as a resource for health information seeking. Whereas people with larger social support networks may have more options of family or friends who can help them seek the appropriate healthcare advice online or refer them to relevant sources (Waring et al., 2018).

Online health forums have become a health information source frequently used by patients (Sudau et al., 2014; Jeong et al., 2018; Willis, 2014). They can provide a platform for individuals with specific chronic conditions to interact with one another, share experiences and provide emotional support (Boot & Mejiman, 2010; Chung, 2014; Jeong et al., 2018; Willis, 2014). They also have the advantage of not being constrained by temporal and geographical boundaries (Chung, 2014). While they can benefit patients, there is also potential to cause harm if inaccurate information is shared. These forums are often run by the public and advice is given by those who are not medically trained (Lederman et al., 2014). Chronically ill patients have reported finding such virtual groups and communities positive with regard to social support, knowledge building and clinical outcomes (Boot & Mejiman, 2010; Chung, 2014; Minto et al., 2015; Willis, 2014). Furthermore, those with long-term conditions, can benefit from easily finding others online who are dealing with the same issues (Chung, 2014).

Previous research has shown that online support groups are perceived to be a popular alternative to face-to-face support groups and other types of informal social support networks, as being online provides 24-hour access and allows the individual to remain anonymous (Coulson et al., 2007; Chung, 2014; Johnston et al., 2013; Plinsinga et al., 2019). Online health forums also provide the opportunity to interact with a diverse community in respect to ethnicity, different points of view and geographic locations (Coulson et al., 2007; Chung, 2014). Reported social support advantages included the feelings of belongingness and reduction in stress (Chung, 2014).

A study adopting an ethnomethodology approach, examined the role of online health communities in arthritis management. Self-management discussions dominated among the members of the group showing they may act as informal self-management education programmes (Willis, 2014). Willis (2014) explained that online health communities have the potential to improve health literacy and possibly health outcomes. However, disadvantages can also arise from using online support networks. The anonymity of online health forums can introduce the increased likelihood of receiving hostile comments and misinterpretation due to non-verbal communication (Coulson et al., 2007). There is also concern about the accuracy of the information people are receiving online (Coulson et al., 2007; Plinsinga et al., 2019). Previous literature has suggested that HCPs should improve their awareness about online health information and communities, so they have further knowledge of the types of informal social support networks patients are engaging with (Tan & Goonawardene, 2017).

Most studies have examined the general use of online health forums (Bell et al., 2011; Chung, 2014; Johnston et al., 2013) while others have looked at specific conditions such as multiple sclerosis (Rupert et al, 2014; Hay et al., 2008). No studies were found which included the observation of heart failure online health forums.

2.5.6 Health status

People with health problems were reportedly more worried about their health status and often attempted to obtain more information on what the disease is, what the consequences are and the treatment options, than those who had no pre-existing health conditions (Minto et al., 2015). Nolke et al. (2015) found that respondents who stated their health status as ‘poor’ or ‘very poor’, were more likely to search the internet for health information as opposed to those who stated their health was ‘good’ or ‘very good’. Rahmqvist and Bara (2007) conducted a secondary data analysis of trends related to the Swedish population of patients retrieving information online. The study found similar results reporting that those who had poorer health, had a higher baseline use of online health information seeking than those in better health. Furthermore, people with poorer health status, were more likely to talk to their HCPs about online health information than those who were in good health (Tan & Goonawardene, 2017).

A cross-sectional study by Oh and Cho (2015) that used data from the US Health Tracking Survey (2012) which recruited 3,014 participants, found that people with chronic diseases had lower levels of resources than healthier people (e.g., employment and income). Furthermore, people with chronic diseases that owned a smartphone, had higher levels of monitoring health conditions and higher income and education levels, were more likely to seek health information online (Oh & Cho, 2015). In the healthy group of people, being female, owning a smartphone and engaging in monitoring health conditions, were all associated with higher online health information seeking behaviours (Oh & Cho, 2015).

2.5.7 Health literacy

A person's health literacy has been highlighted as a factor influencing health information seeking (Plinsinga et al., 2019). Willis (2014) analysed 8231 posts shared on online health communities for arthritis self-management and found evidence to suggest that health literacy is a major determinant of health and possibly explains disparities in health status within populations (Willis, 2014). Health literacy is used to describe an individual's capability to seek, understand and use health information and is context and content specific (Wong and Cheung, 2019). This is relevant to health information seeking as it reflects the necessary skills to acquire information in ways that lead to greater knowledge, with those who have higher levels of health literacy, having higher levels of knowledge (Cajita et al., 2017).

Gutierrez et al. (2014) conducted a cross-sectional survey measuring health literacy and assessing patterns of internet use and health information-seeking behaviour between county (n=265) and private clinics (n=233) in Texas, USA. The health literacy in the county clinic was significantly lower in comparison to most patients in the private clinic having adequate literacy. Elsewhere, a cross-sectional survey of Italian chronic patients (n=352) reported a relationship between health literacy skills and health outcomes (Graffigna et al., 2017). Research has shown that individuals with lower health literacy may have less knowledge about their health issues, higher hospitalisation rates, higher healthcare costs and worse health status than people with adequate literacy (Gutierrez et al., 2014; Graffigna et al., 2017). This is also reflected in the sources individuals use. Those with lower health literacy tend not to use as many sources as those with higher levels of health literacy (Gutierrez et al., 2014).

It was reported that people with lower health literacy had trouble trusting the internet for health information and were also less likely to ask questions or seek further guidance during a medical consultation (Tan & Goonawardene, 2017). The internet has great potential to meet people's health information needs and improve the health literacy of people due to its copious resources, ease of accessibility, cost-effectiveness and more (Graffigna et al., 2017; Tan & Goonawardene, 2017). However, the internet also has potential to mislead and misinform people, especially if the information is provided out of context or misinterpreted (Gutierrez et al, 2014).

2.6 Personal factors affecting online health information seeking

Personal factors can greatly contribute towards an individual's health information-seeking needs and studies have discussed the characteristics of online health information-seekers and self-diagnosers. Van Uden-Kraan et al. (2009) reviewed and reported that *"patients who use the internet for health-related reasons were younger, were higher educated, had a higher income and were more often employed"* (p. 19). A cross-sectional study including 104 patients with or at risk of cardiomyopathy, reported that age, sex, socio-economic status and education level are the most important factors influencing internet-related attitudes (Minto et al., 2015).

2.6.1 Age

Studies shows that there is a direct link with younger age and online health information seeking (Comulada et al., 2020; Gutierrez et al., 2014; Jeong et al., 2018; Litzkendorf et al., 2020; Lustria et al., 2011; Nolke et al., 2015; Smith et al., 2015). The younger generation tended to be more open and willing to using the internet for health-related purposes (Nolke et al., 2015). A Swedish trend analysis study including 24,800 respondents between the age of 20 and 95, reported that internet use by younger females is more common than younger males (Rahmqvist & Bara, 2007).

The gap between younger and older generations of online health information seekers has expanded over time. Older people would increase their use of the internet as a source for health information if the necessary support and training were provided (Haluza et al., 2017).

An online questionnaire survey with a sample of 562 respondents in Austria, found that digital natives (35 years and younger) were more likely to search for the meaning of specific medical terms, their own health status or disease, and diet/weight loss programmes, than digital immigrants (35 years and above) (Haluza et al., 2017). Furthermore, 65.9% of digital natives reported seeking health information online, in comparison to 55.6% of digital immigrants. Additionally, digital natives were more likely to seek additional health information after a HCP appointment (Haluza et al., 2017).

Other studies also found that those middle-aged or younger were more likely to actively seek health information online (Jeong et al., 2018; Nolke et al., 2015). These findings are in line with Samkange et al. (2020) who found that internet use decreased with age as those aged 60 and above were 70% less likely to engage in these behaviours compared to those younger than 30 years. However, Silver (2015) conducted an exploratory semi-structured interview study of patient perspectives on online health information and communication with doctors, among those over the age of 50 years old. This study found that although prior research suggests that older age groups can be less trusting of the internet, some patients reported using the internet instead of visiting the HCP. For these participants, this reluctance to see a HCP was due to previous frustrations and lack of communication.

2.6.2 Gender

Based on the results of related studies, it can be concluded that females use the internet for self-diagnosis and health information seeking, more than males (Gutierrez et al., 2014; Litzkendorf et al., 2020; Lustria et al., 2011; Rahmqvist & Bara, 2007). Additionally, studies recruiting support forum samples have reported a larger number of white female respondents (Bell et al., 2011; Bylund et al., 2007; Tustin, 2010).

Lustria et al. (2011) conducted an analysis of the 2007 US Health information National Trends Survey and found that males were significantly less likely to use the internet for health information seeking than females, which was further supported by a cross-sectional survey conducted in the United Kingdom, Germany, Portugal and Sweden (Samkange et al, 2020).

2.6.3 Education level

According to the literature findings, people with higher level of education attainment are more likely to use the internet to search online health information (Comulada et al., 2020;

Gutierrez et al., 2014; Litzkendorf et al., 2020; Smith et al., 2015; Waring et al., 2018). An American study concluded that individuals with a college background, were more likely to search the internet for health information than those who did not attend college (Lustria et al., 2011).

Those with lower education levels were reported to have reduced odds of relying on the internet compared to those who are more highly educated (Samkange et al, 2020). Additionally, Waring et al. (2018) conducted an observational study in the US with 1142 online patients, and found that those with higher educational attainment, were more likely to share their internet findings with their HCPs.

2.6.4 Income level

Another characteristic that has shown to impact online health information seeking is income level. People with higher household income tended to access online health information more than those with lower household incomes (Gutierrez et al., 2014; Silver, 2015; Smith et al., 2015).

2.6.5 Employment

Those who are of employed status, had a higher tendency to seek online health information than those who did not work (Nolke et al., 2015; Samkange et al., 2020). Additionally, Nolke et al. (2015) found that those with part-time employment, were slightly less likely to seek health information online than those of unemployed status. People who are unemployed were not as likely to rely on the internet (Samkange et al., 2020).

2.6.6 Socioeconomic status

Nolke et al. (2015) found that belonging to a higher social class was a predictor for online health information seeking. Perez et al. (2016) who recruited participants from 21 to 25 years of age, found that participants who had lower socioeconomic status, were more likely to engage in less complex search strategies that involved narrowing their search instead of expanding it. Those who had higher socioeconomic status (with college degrees) were more likely to have complex and more expanded search processes (Perez et al., 2016). As a result of this, individuals with a higher socioeconomic status, were exposed to additional information with a larger number of decision points (Perez et al., 2016).

2.6.7 Ethnicity

Smith et al. (2015) conducted a US national survey and did not find an overall effect of ethnicity however, Asian or Pacific islanders and 'other' ethnicity categories had lower levels of engagement with online health information.

2.6.8 Internet expertise

Similar to employment, education, and income level, people with expert-level use of the internet and those generally experienced in using it, were more likely to source health information (Tan & Goonawardene, 2017).

2.6.9 Stress

Feeling uncertain about one's health can lead to anxiety and worrying (Wang et al., 2018). People often turn to the internet due to uncertainty to try and relieve these concerns however, the feelings associated with uncertainty can potentially be caused by a knowledge or comprehension deficit, in the context of health information seeking (Boot & Meijman, 2010; Caiata-Zufferey et al., 2010). Knowledge deficits can be a key factor that leads to stress and an initial reason for people using the internet in the hope of reducing uncertainty (Boot & Mejiman, 2010).

However, information is not always the answer to reducing feelings of uncertainty as it can also result in increasing uncertainty leading to what is termed 'cyberchondria' (anxiety-amplifying impact of online health searches) (Boot and Meijman, 2010). In contrast, Minto et al. (2015) found that among the 104 participants recruited in their cross-sectional study, patients with a higher internet usage, reported a lower level of anxiety than those with a less intense internet usage.

2.6.10 Sense of self-responsibility

People felt a sense of self-responsibility when it came to managing their healthcare and found the internet to be an aid to help them take control of this responsibility (Caiata-Zufferey et al., 2010).

2.7 Active information seeking and passive receipt of information

Patients receive medical information from HCPs, but they also obtain such information from a variety of other sources such as family, friends, books, news sources and, conveniently, from the internet (Madrigral et al., 2019). Studies of health information-seeking behaviours have explored active information seeking, by seeking to understand why individuals use the internet to gain information (Longo et al., 2010). However, information can also be gained unintentionally (Longo, 2005; Longo et al., 2010). Unintentionally gained information arises when an individual does not actively seek information but comes across it while doing daily activities such as watching television.

Online health forums and social networks can allow individuals to actively participate and engage in forming relationships with other community members. However, individuals can also engage in passive information surveillance by evaluating and observing information without contributions being made (Johnston et al., 2013). Johnston et al. (2013) adopted a multi-method approach by conducting interviews with moderators of 18 online health communities and distributing a field survey of 153 online health community participants. Johnston et al (2013) found that the more actively engaged an individual is with an online community, the more it can lead to informational and social benefits.

Waring et al. (2018) found participants who were in favour of passive types of health information, rated HCPs, pharmacists, family, relatives and friends as more trusted information sources than the internet, newspapers, television and radio.

2.8 Patient-healthcare professional relationship

HCPs have been known to be the main source of primary information (Tan & Goonawardene, 2017). However, patients have now become more likely to look for other types of information resources, such as the internet (Silver, 2015). As people increasingly obtain online health information and become active participants in their own healthcare, the patient-HCP relationship changes accordingly (Silver, 2015; Haluza et al., 2017).

Paternalistic relationships were once the norm. However, as patients become more informed about their healthcare, HCPs are having to adapt their role and grow with technological advances such as the increasing participation in health information seeking (Dahl & Eagle, 2016). Studies report that while some HCPs have been receptive to better informed patients, others have reported feeling their expertise is being overlooked and devalued (Dahl and Eagle, 2016). However, Silver (2015) found that some patients held their doctors in high regard and were afraid to say the wrong thing, highlighting the hierarchical relationship between doctors and patients.

Bell et al. (2011) conducted an online survey to find predictors of post-appointment online health information seeking. Trust in the HCP was related to going online, but even when people reported trusting their HCPs, they still used the internet after the appointment to research their health circumstances (Samkange et al., 2020). A semi-structured interview study involving 28 patients recruited from waiting rooms in 14 medical practices in Switzerland, found that all patients who searched the internet, used it as a complimentary source and did not question the competency of the HCP as a result of doing so (Caiata-Zufferey et al., 2010).

Almost half of those accessing internet health information, do not share the information with their HCPs (Dahl & Eagle, 2016) and this drops to less than 20% for those with chronic conditions (Bartlett & Coulson, 2011). A questionnaire study found that 378 out of 400 of respondents did not discuss their online health information with their HCPs at least some of the time. This was due to not wanting to embarrass themselves or feeling there was not enough time in the appointment, which resonates with other studies (Lee et al., 2015; Lu et al., 2018; Tan & Goonawardene, 2017). People who identified embarrassment to be a barrier, did not feel they had the skill set to evaluate online health information accurately and had lower confidence in the credibility and trustworthiness of online health information (Tan & Goonawardene, 2017).

Using the internet to seek health information can cause issues due to fear of damaging the patient-HCP relationship as people have concerns about HCP disapproval which can cause patient anxiety, confusion and frustration (Laugesen et al., 2015; Silver, 2015; Tan & Goonawardene, 2017). On the other hand, HCPs reported generally accepting that the internet may lead patients to becoming more informed and are aware that patients may be conducting online searches. Four out of ten HCPs believe that it may damage the patient-HCP relationship (Laugesen et al., 2015). Additionally, they worry that it will lead to patient confusion and unrealistic expectations of their treatment options and care (Laugesen et al., 2015; Wang et al., 2018).

Online health research can often reflect patient's dissatisfaction with a HCP or a consultation (Tan & Goonawardene, 2017). However, many people who searched online before the appointment and then shared the information with their HCP, felt it positively affected their relationship (Tan & Goonawardene, 2017). Furthermore, Haluza et al. (2017) reported that a quarter of their participants agreed that online health information allowed them to communicate more efficiently with their HCPs. Overall, HCPs were still viewed as the most valuable source of health information for patients (Caiata-Zufferey et al., 2010; Tan & Goonawardene, 2017; Farnood et al., 2020).

2.9 Patient outcomes

Having accessibility to a wealth of online health information has led to people feeling self-sufficient, competent and empowered in managing their own healthcare and engaging in discussion with HCPs (Waring et al., 2018). Furthermore, Tan and Goonawardene (2017) conducted a systematic review on patient's internet health information seeking and how it impacts the patient-physician relationship. The study reported that sharing online health information with HCPs allowed patients to feel not only more empowered, but also an improvement in the quality of discussion between the patient and HCP.

From a patient perspective, online health information has been shown to have both positive and negative effects. From a positive viewpoint, the most cited effect is patient empowerment (Laugesen et al., 2015), indicating that having access to a vast amount of internet health information can provide a sense of empowerment, control and higher patient satisfaction (Laugesen et al., 2015). Laugesen et al (2015) conducted a survey-based study consisting of 225 participants and reported that patient empowerment has the potential to increase confidence to communicate more effectively with their HCPs and lead to better health outcomes.

Patient's felt more confident in the consultation when bringing their internet findings to the HCP (Tan & Goonawardene, 2017) and it has been reported to help empower patients in taking a more active role in disease management (Willis, 2014; Tan & Goonawardene, 2017). Furthermore, patient empowerment was further influenced by how receptive the HCPs were for the patient to take part in the decision-making process (Tan & Goonawardene, 2017).

2.10 Chapter summary

Online health information has been said to help people self-manage their health and feel more empowered and in control (Willis, 2014; Tan & Goonawardene, 2017). Online self-diagnosis and health information seeking also encourages the development of social and personal aspects of health as more awareness is sought regarding an individual’s health status (Rahmqvist & Bara, 2007). The rapid proliferation and increasing availability of online health information, allows users to overcome any geographic factors and limits costs that can come with traditional methods of health information (including transport costs) (Boot & Meijman, 2010). Additionally, individuals can acquire knowledge of their health status prior to visiting a HCP (Comulada et al., 2020). Researchers have shown that personal and contextual factors influence online health information seeking behaviour such as the sense of self-responsibility and the opportunity to use the internet efficiently (Caiata-Zufferey et al., 2010).

The literature comprised of studies of varied methods from systematic reviews, cross-sectional surveys and qualitative semi-structured interviews. The reported literature suggests that access to internet health information may widen health inequalities and older adults, those with lower health literacy, less education and lower socio-economic status may be disadvantaged with access to online health information.

No previous research was found exploring heart failure related online health forums or specifically focused on heart failure patients as online health information seekers. One study analysed the quality and health literacy demand of heart failure online health information (Cajita et al., 2018).

The following chapter discusses the methodological basis for the choices made in formulating the research design and operationalising the study, situating them within the relevant literature.

Chapter 3 - Literature pertaining to the methods

3.1 Introduction

The aim of this chapter is to discuss the methods used in this thesis and the rationale for choosing the different approaches. The chapter explains the research paradigms that have shaped most research endeavours - firstly naturalism and positivism, then interpretivism and finally critical realism. The reason for not using quantitative methods such as a questionnaire survey is explained. The chapter also discusses the role of mixed and qualitative methods in nursing and health research. First in broad terms and then narrowing it to consider qualitative descriptive research – one of the approaches taken for the present study. The field work for the research reported in this thesis took place during the abnormal circumstances of the COVID-19 pandemic, which brought face-to-face data collection to a halt. In response to this, the research design was adapted, and online data collection was implemented for interviews. Hence, online interviews are discussed at length as well as the semi-structured format that was chosen for these interviews. The approach chosen for data analysis, thematic analysis, is explained and its use justified. Finally, the data was conceptualised through the Normalization Process Theory (NPT) framework, the theoretical underpinning to this study, which is discussed in-depth.

3.2 Research paradigms and the approach to reality and knowledge

In research, a paradigm is a set of assumptions and associated practices, which serve to explain how an individual perceives the world. These paradigms offer a roadmap guiding both the researcher’s thoughts and corresponding actions (Atkinson, 2011). They are likely to influence the choice of research problems, the formulation of research questions and the choice of methods and the approach to interpreting the results/findings.

The two main methodologies used by researchers are qualitative and quantitative. Qualitative studies observe a naturalistic paradigm, whereas quantitative ones align with the positivist paradigm (Polit & Beck, 2014). It is often assumed that qualitative approaches are commonly associated with interpretive and critical paradigms, and quantitative is drawn on positivist ontologies. An emerging paradigm is the critical realist paradigm – where the researcher understands that all observations are subject to error and all theory is revisable (Parahoo, 2014). These different paradigms are discussed in this chapter.

Researchers studying the social world invariably view it as necessary to define the ontological assumptions underpinning their work, as this affects epistemology, methodology, the methods used and ultimately research design (McPhail & Lourie, 2017). Research, including nursing and health research, occurs within a set of assumptions and beliefs on the nature of reality, knowledge and the role of research in achieving understanding. These assumptions and beliefs are referred to as a research paradigm and the researcher's adopted paradigm will determine their methodological strategy (Corry et al., 2019). For this reason, this section discusses the principal research paradigms – naturalism, positivism and interpretivism – before explaining critical realism, the present study's selected paradigm.

3.2.1 Naturalism and Positivism

When science replaced the philosophy of rational knowledge, positivism became the dominant philosophical system (Dharasmi & Scott, 2009). The source of all knowledge was our sensory experiencing of the natural world through which we establish verified facts. Positivism is the assumption of a straightforward relationship between the world and our perception of it. Knowledge is verified by hypotheses and established as laws or facts (Lincoln et al., 2011). This ontological naturalism is based on "the thesis that there is (or can be) an essential unity of method between the natural and the social sciences" (Bhaskar, 1998). The positivist view holds that the world comprises of absolute truths which exist independently of human consciousness and knowledge and is there to be discovered by experimentation (Dharamsi & Scott, 2009). McKenna (1997) encapsulates the positivist approach thus,

> Our minds interpret the world through our senses, and because the world is subject to the laws of science, events outside the mind can be observed, described, explained and predicted. Therefore, to make sense of the outside world all we had to do was to observe it (p. 121).

An increasingly strong critique of positivism is based on researcher objectivity which those who took an anti-positivist stance viewed as unrealistic (Lincoln et al., 2011). They argued that when taking a magnifying glass to a social phenomenon, the researcher is inevitably looking through their own subjective lens, a subjectivity that is present right from the choice of research problem to the conclusions drawn (Bryman, 2012). Corry et al. (2019) concluded that positivism should no longer be considered a “foundational philosophy” in healthcare research, labelling it “anachronistic”. Much of the critique comes from perspectives which could be grouped under the interpretivist paradigm.

The features of positivism include viewing research as a sequence of logical steps, using rigorous and multiple methods of data collection and analysis, and relying on facts that can be external and objective (Collins & Stockton, 2018). Methods commonly linked to this paradigm include experiments and survey research. Quantitative research can include longitudinal, randomised controlled trials. For example, drug or vaccine trials can take a long time to study the impact and effects of an intervention on variables measured. Quantitative researcher paradigms do not consider the respondents perspectives and experiences (Bryman, 2017).

Naturalistic approaches focus on understanding the human experience. Naturalism is applied by exploring narratives and subjective reports and approaches common to qualitative research (Polit & Beck, 2014). Naturalism requires more flexible research structures that can readily capture the meanings that emphasise human interactions and decipher what is perceived as reality (Parahoo, 2014), unlike structural frameworks preferred in positivist research. Naturalism encapsulates people’s words and actions. The paradigm focuses on discovering patterns and meaning from within the data (Parahoo, 2014; Kivunja & Kuyini, 2017).

Positivism and naturalism approaches are not necessarily appropriate in isolation in research. Combining both positivist and naturalist approaches, can provide a deeper insight into understanding the phenomenon. Hence, critical realism has emerged to address both positive and negative elements of the positivist and naturalist paradigms.

3.2.2 Interpretivism

Interpretivism, sometimes termed constructivism, rejects the positivist philosophy and its stance on researching the social world. For much of the 20th century, positivism remained dominant until new perspectives emerged under the interpretivist umbrella including ethnomethodology, symbolic interactionism, feminism, phenomenology, and Marxism. With these new approaches came new methods and, in particular, more qualitative research was conducted (Bryman 2012). An interpretivist researcher tasks themselves with making an interpretation of how their research subjects interpret reality (Schwandt, 1994). The new approaches all had in common the basic assumption that the social world can be objectively observed as a false one as subjectivity was unavoidable. An interpretivist researcher develops a subjective understanding of social phenomena by interpreting the perspectives of the research subjects (Bryman, 2012). A definition is offered by Atkinson (2011), who describes the interpretivist paradigm thus,

> …interpretivism is a paradigm that provides an organised set of assumptions about the nature of reality and how to study that reality through empirical methods. It focuses on how people make sense of the world around them, and over the course of time how collective definitions of reality shape and direct human thought and behaviour. (p.117)

One of the central debates concerning interpretivism is whether or not the findings of interpretivist research are generalisable. In principle, a set of findings from a particular interpretivist study may be relevant to that group of participants alone (Atkinson, 2011).

3.2.3 Critical realism

Critical realism has been described as "the view that entities exist independently of being perceived or independently of our theories about them" (Phillips, 1987, p.205). The critical realism paradigm has become a feasible option for capturing meaningful research, particularly research within the social and practice-based sciences such as nursing (Schiller, 2016). Critical realism has also become recognised as a philosophical paradigm for mixed method approaches to research (Schiller, 2016). The paradigm supports both quantitative and qualitative research methods within a single study.

Reality and the value-laden observation of it, operate in two separate dimensions: the intransitive; and transitive. The intransitive dimension is natural and constant whereas the transitive dimension is evolving, social and historical (Varaki & Earl, 2005). Bhaskar argued that greater meaning could be achieved through a thorough and accurate description of a phenomenon than seeking an 'absolute truth' (Williams et al., 2017). The emphasis is on finding what makes an observable phenomenon occur or change. Therefore, this paradigm is well suited to this PhD project.

In ontological terms, critical realism is based on a belief that a world exists that is entirely independent from the human understanding of it. It is epistemologically positive, in contrast to interpretivism, as it supports the objective scientific value of research, albeit with a reliance on judgemental rationality, a process in which the explanatory power of particular knowledge is evaluated (McPhail & Lourie, 2017).

Critical realism was proposed as an alternative to the prevailing paradigms of positivism and social constructionism (Hoddy, 2019). Under critical realism, reality is stratified into three domains. The first is the ‘real’ domain which consists of natural and social objects, structures, and associated mechanisms. Second is the ‘actual’ domain which is made up of the events which occur when the mechanisms are engaged. Third is the ‘empirical’ domain which comprises our experiences and perceptions of these events (Hoddy, 2019). The stratified reality is illustrated in Figure 3-1.

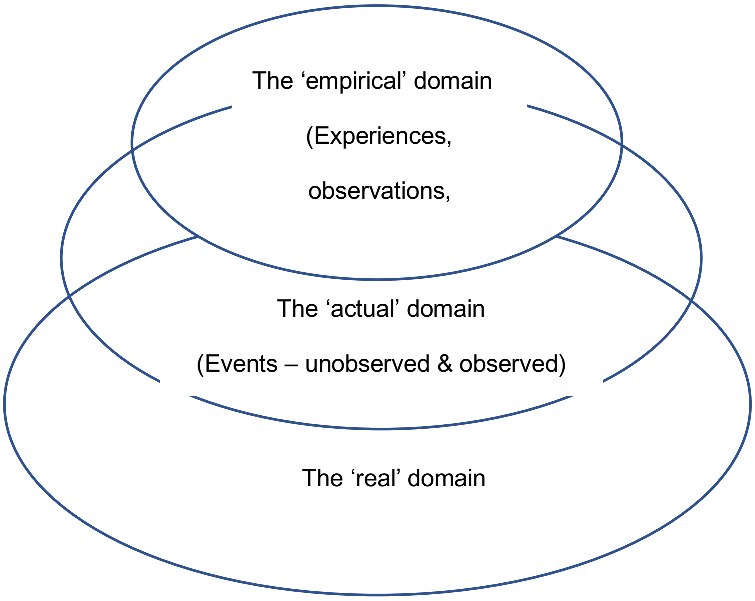


Figure 3-1: The stratified view of reality
Source: Based on Hoddy (2019, p.119)

Critical realism’s main relevance to researchers is its middle way between the structures of positivism and the rejection of objectivity found in post-modernist approaches to social sciences. It can be viewed as a combination of interpretive epistemology and ontological realism (Bygstad et al., 2016). While there is an objective reality which exists separately from our interpretation of this reality, the way we understand it is socially constructed. Hence it has some commonality with positivism through its acknowledgement of an objective reality, but also some with interpretivism as it recognises the limits to the extent this objective reality can be objectively observed (Hoddy, 2019).

There is a growing body of health research conducted from within the critical realism paradigm. The framework has been applied to a wide range of health-related studies (Byng et al., 2005; Marchal et al., 2010; Parlour & McCormack, 2012; Tolson et al., 2007; Wand et al., 2010; Wilson & McCormack, 2006). Best et al. (2016) applied the critical realist framework in a study of online help-seeking among adolescents in Northern Ireland. Williams, Rycroft-Malone, and Burton (2017) summarise their evaluation of Bhaskar's contribution thus,

> Bhaskar was interested in human emancipation, and we suggest his work is of great importance to advance nursing and healthcare knowledge of understanding complex social situations. Bhaskar's work focuses our attention on the interplay between structure and agency and on the search for generative mechanisms. (p. 9).

Table 3-1 summarises this discussion of the three paradigms: positivism, interpretivism and critical realism.

Table 3-1: Main philosophies of social research

	Positivism	**Interpretivism**	**Critical Realism**
Ontology	An objective independent reality where causality is demonstrated through the conjunction of empirical events.	Reality is socially constructed. Multiple realities can exist.	An objective but stratified reality with structures and mechanisms and causal properties.
Epistemology	Knowledge generation through discovery of general laws and relationships between variables that have a power to predict. Emphasis on prediction.	Knowledge generation through interpretation of subjective meanings and behaviours of subjects seen through their own lens. Emphasis on interpretation.	Retroductive reasoning applied to theory building. Emphasis on explanation.
Methodology	Quantitative methods, including, surveys, experiments, and use of secondary data in statistical analysis.	Qualitative methods including ethnographies and case studies.	Not prescriptive for methods with selection based on research question, scope for mixed methods.

3.2.3.1 Retroductive reasoning

The research paradigm includes a method of reasoning. Positivism is associated with deductive reasoning. A researcher starts with theory, formulates hypotheses, collects observations in the form of specific data and then confirms whether or not they prove the hypotheses or not and hence whether the theory is supported (Glynos & Howarth, 2007). As a result, deduction is closely associated with the justification and verification of existing theories. Interpretivism, in contrast, is associated with an inductive approach which starts with the making of observations, attempts to establish patterns among the data then proposes findings which in turn lead to theories or generalisations (Bryman, 2008). Philosophers undertaking critical realism do not necessarily reject these two methods of reasoning but instead propose that when building a theory, a more abstract reasoning process should be added, particularly retroduction and abduction. Retroduction uses description and analysis of a particular phenomenon to identify the basic conditions for its existence. Its aim is to provide the nearest best description of a social phenomenon (Williams et al, 2017).

Abduction is used to recontextualise and interpret particular phenomena. Modell (2009, p.213) explains that “abduction does not move directly from empirical observations to theoretical inferences, as is the case in purely inductive research, but relies heavily on theories as mediators for deriving explanations”. Both retroduction and abduction are forms of inference and ways of conceptualising the outcome of which is the development of an original conceptual model or theory. They are often used together to add innovative approaches to analysis and can also complement deductive reasoning (Meyer & Lunnay, 2013). Literature searches have suggested an underrepresentation of retroductive/abductive reasoning in nursing literature when compared to induction and deduction (Lipscomb, 2012). Nevertheless, abduction as a method of reasoning may be more suited to nursing than alternatives due to the “extremely dynamic environments” (Lipscomb, 2012, p.249) in which nursing activities take place.

3.3 Deciding against quantitative methods

Most researchers face a decision whether to adopt quantitative, qualitative or mixed methods. The main features of quantitative research are its use of numerical data, its positivist adherence to the principles of the natural sciences and its support for objectivism. Quantitative researchers are mainly concerned with measurement, causality, generalisation and replication (Bryman, 2008). Quantitative health research is commonly in the form of observational studies, surveys and clinical trials (Tariq & Woodman, 2013).

Quantitative methods in the context of the present study would have likely meant some form of survey. Indeed, many researchers do effectively use a survey questionnaire when conducting psychosocial research in the medical and health field (Lauri, 2019). In the circumstances of the COVID-19 lockdown and subsequent social distancing, a survey administered online would have been the most likely option. Such an approach would be suitable for questions of prevalence of the behaviour of interest and other related quantifiables (White & Horvitz, 2009). The accuracy of self-diagnosis can also be addressed quantitatively; for example, through a cross-sectional survey (Jutel et al., 2011). Technological readiness and attitudes toward self-diagnosis tools have also been surveyed with the Technology Acceptance Model as the theoretical framework (Lanseng & Andreassen, 2007). Quantitative methods are generally useful for establishing the predictive power of independent variables (Shmueli & Koppius, 2011). Surveys are ideal for understanding the characteristics of large populations but less suited to understanding attitudes and behaviour (Bryman, 2008). The researcher must consider their research question(s) and reflect on which methods are most likely to address it/them in a way that will advance understanding of the phenomenon of interest (Bryman, 2008). As other researchers have done, it was concluded that a quantitative questionnaire survey would not capture the depth of detail required on what participants want to voice in this thesis about the phenomenon that was being studied (Lauri, 2019).

Quantitative research has been critiqued for not distinguishing between humans and their social institutions. Another critique concerns the reliance on procedures and instruments which is argued to create a barrier between research and normal day-to-day life. Quantitative research analyses relationships between variables at a given point in time. Similarly, participants responding to a survey are constrained in their responses to selecting a response from a list or scale that is determined by the researcher (Wilkinson et al., 2004).

Nursing research is not a binary choice between quantitative and qualitative methods. Health researchers have been increasingly interested in combining both approaches in mixed method studies (Morgan, 1998). As Kaur (2016) explains, “Mixed method research intentionally integrates quantitative and qualitative methods rigorously to draw on the strengths of each other to ensure that the results of a study are more close to reality" (p. 96). Further support for mixed methods comes from Tariq and Woodman (2013) who explain,

> Mixed methods research therefore has the potential to harness the strengths and counterbalance the weaknesses of both approaches and can be especially powerful when addressing complex, multifaceted issues such as health services interventions and living with chronic illness. (p.3)

However, this search for triangulation can lead to disappointment when quantitative and qualitative findings fail to come together in the expected manner (Kaur, 2016).

A hoped-for benefit is sequencing whereby, for example, survey results can guide the development of an interview schedule or interview data can inform survey design (Morgan, 1998). Mixed methods is not without its critique. There are subjective judgements involved in whether or not to prioritise one type of data with the other having a more supportive status. Furthermore, it does mean operating within two totally contrasting paradigms (Creswell, 1994), though pragmatists and those taking a critical realist approach may argue that this is entirely plausible.

Quantitative evidence on health seeking behaviours seems readily available based on literature searches and this, combined with consideration of the types of research questions set for the present study which aim to explore and describe the perceptions of both patients/public and HCPs, pointed strongly towards a mixed methods/qualitative design. A mixed-methods systematic review was constructed which led to qualitative descriptive research and an online interview study. Choice of methods is mainly determined by research questions which are in turn devised based on the literature review and a process of reflection on the research problem (Whitehead et al., 2016).

3.4 Qualitative methods in health research

In contrast to quantitative research, qualitative research mainly gathers data in the form of words. Qualitative research is widely used in nursing and midwifery where the aim is to make sense of human reality and achieve the joint objectives of a rich description and theory development (Holloway & Galvin, 2016; Whitehead et al., 2016).

Qualitative research is “an empirical method of investigation aiming to describe the informant's perception and experience of the world and its phenomena.” (Neergaard et al., 2009). Health researchers use qualitative methods for identifying problems, generating hypotheses, formulating theories and developing concepts. Such methods are particularly suitable for addressing “what, “how” and “why” questions related to human behaviours, perceptions and motivations (Neergaard et al., 2009). Qualitative methods enable us to develop an understanding of why humans act or refrain from acting in a particular way. In the present study, I sought to understand the phenomenon of online self-diagnosis and health information seeking and the effect it may have on the patient-HCP relationship. Unlike the constraints on expression that a questionnaire survey brings, qualitative data collection methods allow participants freedom to express themselves however they wish (Wilkinson et al, 2004).

There are four main strands to the critique of qualitative research (Bryman, 2012). Firstly, there is the issue of objectivity. It is argued that qualitative methods can be biased starting with the choice of research question through to the discussion of the main findings (Bryman, 2012). Secondly, there is the replicability issue where it is argued that qualitative studies are subject to researcher subjectivity where another researcher aiming to repeat the study in a different setting or at a different time, would be unlikely to arrive at the same findings (Bryman, 2012). To counter this, qualitative researchers should make extra effort to set out precisely how the study was conducted. Thirdly, is the issue of generalisability, whether findings are transferable from one setting to another, which can be problematic due to the nature of the data generated by qualitative methods. In response, there have been efforts to redefine the concept of generalisability to fit better with qualitative research. Lincoln et al (2011) proposed the term transferability to replace generalisability, while Sarantakos (2012) refers to “fittingness”, arguing that researchers should carefully evaluate findings to judge whether they would fit in another setting or point in time. A fourth source relates to transparency (Bryman, 2012), with some qualitative research lacking explicitness in how samples were selected and how conclusions were arrived at. Sarantakos (2012) also highlights the potentially time-consuming nature of qualitative research and due to the closeness of researchers and participants, the potential for ethical issues to arise.

In response to these, a range of analytical frameworks have been proposed to improve the rigour of qualitative research from grounded theory (Strauss & Corbin, 1997), to Eisenhardt’s (1989) case study design to Braun and Clarke’s (2006) framework for thematic analysis. Tools and strategies were applied in this research to ensure rigour in the work. How these were applied when operationalising the study within the PhD project is presented in Chapter Four. The present PhD research aimed to obtain rich descriptions of how the patient-HCP relationship is affected by the use of online self-diagnosis and health information. To achieve this, qualitative methods were deemed to be appropriate based upon the evidence from the literature.

3.4.1 Qualitative descriptive method

Qualitative description is defined as “a description of informants' experiences in a language similar to the informants' own language (Neergaard et al., 2009, p.2) and further explained by Sandelowski (2000, p.334),

> Qualitative descriptive designs typically are an eclectic but reasonable combination of sampling, and data collection, analysis, and re-presentation techniques. Qualitative descriptive study is the method of choice when straight descriptions of phenomena are desired.

Bradshaw et al. (2017) add that it is the aim of qualitative descriptive research to reach an in-depth understanding firstly through a description and secondly through analysis and interpretation of the meaning’s individuals assign to events. Qualitative descriptive is the clear choice when the main purpose of the research is to provide a thorough description of a phenomenon (Neergaard et al., 2009). Qualitative health researchers often adopt phenomenology, grounded theory, ethnography or narrative approaches particularly when their work is theory driven. Qualitative descriptive is one of the least theoretically based forms of qualitative research (Neergaard et al., 2009). Another difference between qualitative descriptive and other qualitative approaches is that interpretation and inference is minimised and description using language reflective of informants’ own language is prioritised. Whitehead et al (2016) explain that qualitative descriptive researchers “collect rich narrative data from small sample populations and analyse that data thematically using broad free-form methods” (p.95).

Sandelowski (2000) explains that descriptive qualitative research is less interpretive than phenomenological, ethnographic and grounded theory approaches and focuses on presenting the facts in an easy-to-understand way. Rather than going beyond the data with interpretation, the goal is to remain closer to it and closer to “the surface of words and events” (Sandelowski, 2000, p.336).

Neergaard et al. (2009) addresses the question of the status of descriptive qualitative research in relation to other forms of health research. The most common critique of qualitative descriptive is its lack of credibility and rigour. However, such deficiencies are not inevitable, and it is in the hands of the researcher to conduct and report their study in a way that maximises transparency and rigour (Neergaard et al., 2009). A further limitation is cited as the absence of theory and as a consequence, the analysis could be viewed as an advantage by facilitating a 'no strings attached' analytical process (Neergaard et al., 2009). Milne and Oberle (2005) propose a set of four strategies for enhancing the rigour of qualitative descriptive research. These are summarised in Table-3-2.

Table-3-2: Strategies for rigorous qualitative description (based on Milne & Oberle 2005).

Authenticity	**Credibility**	**Criticality**	**Integrity**
• Informants speak freely • Flexible purposive sampling • Participant-driven data collection • Strive for richness of data • Represent participants' contributions accurately • Transcribe interviews accurately • Content analysis	• Capture and portrayal of a genuine insider perspective	• Reflects on and explains critically each of the research methods decisions	• Reflect on researcher bias • Dual role clinician/ researcher when interviewing and analysing • Participant validation/checking • Peer review/researcher triangulation

Most commonly, qualitative description collects data through semi-structured interviews which could either be in a one-to-one format or group interviews (Neergaard et al., 2009).

Magilvy and Thomas (2009) describe the use of qualitative descriptive approaches in health research as the form of qualitative research that is "well-suited to produce a positive and successful experience in this type of research" (p.299). According to Leurer and Misskey (2015), qualitative descriptive is "a method useful in exploring the experiences of health care system consumers" (p.3). Both are important justifications for choosing this approach.

3.5 Online interviewing

For qualitative researchers, the most common method of collecting data is the interview (Austin & Sutton, 2014). In qualitative research, the face-to-face interview was considered the gold standard for collecting data (Krouwel et al., 2019). In this research, the original intention was to offer online interviews as an option for those participants who preferred that to face-to-face interviews. There was also a plan to gather data from focus groups and face-to-face interviews. Chu et al. (2017) had chosen this option when investigating online health information seeking behaviour. However, as the fieldwork for the present study was conducted during the COVID-19 pandemic, it was decided to adopt entirely online data collection. As a piece of digital health research investigating online self-diagnosis, this seemed particularly appropriate.

Online research methods are increasingly presenting researchers with versatility and methodological flexibility across a wide range of research fields (O'Connor et al., 2008). Online surveys are increasingly favoured for quantitative studies and a range of interview techniques using the internet have been developed for qualitative research (Breines et al., 2021). The COVID-19 pandemic has brought the potential of the internet into sharp focus as traditional fieldwork was suspended in most parts of the world. In line with other activities, online solutions were sought to maintain some level of activity.

There are two main ways of classifying online interviews. The first is whether the format is one-to-one or a group interview like a focus group. The second is between asynchronous (not in real-time) and synchronous (in real-time) interviews. Examples of asynchronous online interviews are those using e-mail, bulletin boards and discussion forums (Janghorban et al., 2014). Synchronous interviews take place either via text-based live chat applications or video calling using applications such as Skype, Facetime or Zoom. Video calling has the advantage of being able to hear and see the interviewee and for the interviewer to see and hear the researcher. Equally advantageous, video calling is significantly lower cost, both financially and timewise, than 'in person' interviewing (Janghorban et al., 2014). Conducting interviews over the internet saves on travel costs and reduces the problems of finding convenient times and locations for the interviews (James & Busher, 2006).

Janghorban et al. (2014) conducted a qualitative study of people with irritable bowel syndrome which compared the quality of data collected through video call interviews and traditional in person interviews. Data quality was marginally higher for the traditional in person interviews, however, this may in some circumstances be outweighed by the time and cost benefits. They conclude that video call interviewing is a viable research method either on its own or combined with in person interviews (Janghorban et al., 2014).

Email interviewing is a type of qualitative research that may be beneficial for some participants as it allows them to respond to questions at a time of their choosing and may reduce any potential for stress from being interviewed (Fritz & Vandermause, 2018). Commonly, interview questions are sent individually or in batches to not overwhelm participants (O'Connor et al., 2008). Some participants may value having the questions sent one at a time though others may forget their earlier responses and end up producing discontinuous responses (James & Busher, 2006). A further advantage is that email technology is straightforward and has been in common usage for decades. Email interviews may be dry as there is no interaction which could resolve the meaning of questions or responses. Furthermore, when answering emailed questions participants may be distracted leading to rushed or incomplete responses (James & Busher, 2006). Overall, for the present study the disadvantages of email interviewing were judged to outweigh the benefits.

Text-based interviewing means using an online instant messaging application such as Messenger. A notable attraction of this method was that the need for time consuming transcription would be removed as a written record of the interview would be retained within the application that could be subsequently accessed for analysis. Other suggested advantages include the ability to review the text before clicking send (Crichton & Kinash, 2003). Krouwel et al. (2019) suggest that instant messaging may be particularly useful for certain populations for whom face to face communications are challenging such as those with Autistic Spectrum Disorder. However, this method also has significant drawbacks. According to Jowett et al. (2011), using online instant messaging software for research interviews results in stunted transcripts with only half the words of standard face-to-face interviews. Another drawback is the difficulty faced by the interviewer in trying to establish rapport with the participant, something considered important for effective interviewing (Shaw, 2010). There is a lack of opportunity for empathetic or encouraging communication or nonverbal cues and an inability to discern whether a participant has been interrupted or is merely pausing for thought (Crichton & Kinash, 2003).

Having reviewed the strengths and weaknesses of email and instant messaging interviews, it was concluded that online synchronous video interviewing was likely to produce the highest quality data. However, despite its obvious potential, online video interviewing is not without its dilemmas. At the earlier stages of internet use there was concern that online interviewing would lead to skewed samples as not everyone had internet access (Curasi, 2001). However, now in the 2020s in many countries internet access is approaching universality. By 2019, in the UK, the internet was accessible to 93 per cent of households (ONS, 2019). While elderly people may make less use of the internet among other age groups, access is highly prevalent, and any possibility of skewed samples is manageable.

Deakin and Wakefield (2014) recounted their experiences of using Skype interviewing for their qualitative doctoral research. They highlighted the advantages as being flexibility for interview timings, time and cost effectiveness, and the choice of audio or video. Against this they found the disadvantages to be the potential for unfamiliarity with Skype, a potentially lower level of commitment among participants as it is so easy to drop out at the click of a mouse, and participants possibly feeling ill at ease being filmed in their own house (Deakin and Wakefield, 2014). Ayling and Mewse (2009, p. 575) conclude that “online qualitative research is valuable in its own right, and that the advantages considerably outweigh the difficulties”. Online interviewing has gained widespread acceptance in the research community with O’Connor and Madge (2017) describing it as “valued in and of itself as a valid and legitimate research method” (p. 422). Online interviewing allows for a full range of verbal and visual exchanges and so closely resembles face-to-face interviewing (Salmons, 2012). Among the challenges anticipated were the availability of participants at the pre-arranged times and the possibility for technological/ user glitches. In the present study, I had access to multiple applications including Zoom and Skype to ensure there was an application that the participant was familiar with. In line with the steps taken to uphold high ethical standards, participants gave their consent for the interview to be recorded.

3.5.1 Semi-structured interviews

Whether an interview takes place in-person or online, the researcher must decide upon the type of structure to be used. While the main labels given to interviews tend to be unstructured, semi-structured and structured, it is more accurate to speak of a continuum from survey style fully structured interviews through to unstructured, in-depth interviews which give the interviewee free reign to talk broadly on a subject (Stuckey, 2013; Jamshed, 2014). In reality, most empirical research interviewing falls between these two and is generally referred to as semi-structured. Fylan (2004) offers a straightforward description,

> Semi-structured interviews are simply conversations in which you know what you want to find out about – and so have a set of questions to ask and a good idea of what topics will be covered – but the conversation is free to vary and is likely to change substantially between participants (p.65).

In a semi-structured interview, the researcher normally prepares an interview schedule (or guide) beforehand consisting of the main questions, follow-ups and prompts. It is advisable to test the interview schedule through one or more pilot interviews (Kallio et al., 2016). This schedule is kept to hand during the interview and its main purpose is to ensure that the important areas of interest are covered. The schedule is not read from without thought and the researcher may choose to deviate from it if they wish to pursue a particular thread. A benefit of online interviewing is that the participant may not see the schedule at all as it can be off screen which could add to the sense of spontaneity. Unlike, for example, a fully structured research interview it is not essential that the exact wording of the questions is the same for every interview. Furthermore, the participant is given sufficient latitude to pursue lines of thought that the interviewer may not have anticipated beforehand, or which are judged to be particularly insightful. The questions used are invariably open questions that cannot be answered with a simple ‘yes’ or ‘no’ because the researcher is seeking rich, in-depth descriptions of the phenomenon of interest (Bryman, 2012). In common with many other researchers, I opted to use a semi-structured format as it offered the right degree of flexibility and the best opportunity to arrive at a rich description of the phenomenon of interest.

To maximise the effectiveness of this method, it is important to consider what methodological problems have been associated with qualitative research in which the data has been gathered via semi-structured interviews. Semi-structured interviews have been described as requiring more sophisticated interviewer input, as well as being labour intensive and time-consuming (Adams, 2015). Diefenbach (2009) highlights that interviewees may be influenced by the interview situation and become unreliable sources due to an unconscious bias. Furthermore, in some cases there may be deliberate and conscious attempts at misleading the interviewer (Diefenbach, 2009). Also, there may be unsystematic and subjective methods used to select participants. During data analysis there could be no objective criteria used for selecting and grouping the data (Diefenbach, 2009). On this latter point, it was ensured that the data analysis process was as systematic as possible. The following section describes the process to be used in the present study. Despite the potential pitfalls, the semi-structured format has been widely and effectively used in health research and was chosen for the present study to achieve a balance between allowing participants the latitude to pursue their thought process while at the same time ensuring that the data generated was relevant to the research questions.

This research identified a set of research questions that needed to be addressed. Hence the researcher needed to introduce a degree of structure to the interviews to ensure that the interviews did not wander off onto areas beyond the scope of the present study. Had an unstructured format been adopted then this may well have happened. On the other hand, if the format had comprised a list of questions to be asked of each participant using the same wording in the same order then important insights could have been missed.

3.6 Thematic analysis

Qualitative data analysis has been defined as “working with the data, organising them, breaking them into manageable units, coding them, synthesising them, and searching for patterns” (Bogden & Biklen, 1982, p. 145). There are several established approaches to the analytical task in qualitative research. These include the framework approach, grounded theory, phenomenology and ethnography, among others. Grounded theory was not used as it tends to be associated with research which prioritises the development of hypotheses and theory (Strauss & Corbin, 1997). Phenomenology is more suited to study designs relying on in-depth interviews and not the triangulated approach used here (Balls, 2009). This research is also beyond the definition of ethnography (Roper & Shapira, 2000) so ethnographic methods would be inappropriate. The framework approach (Ritchie & Lewis 2003) could have been used for the present study, it has considerable similarities to thematic analysis. The Braun and Clarke (2006) method was chosen due to the straightforwardness of understanding and describing their 6-step approach. Debates among qualitative researchers as to the merits of a particular approach tend to centre on rigour and the search for trustworthiness (Nowell et al., 2017) but also acknowledge the similarities that exist between them. For example, the framework approach is commonly used in nursing research and is based on thematic analysis (Smith & Firth, 2011). What Braun and Clarke (2006) proposed was that thematic analysis should itself be viewed as an approach alongside the aforementioned.

The patterns identified in qualitative data are generally referred to as themes and the process referred to as thematic analysis. Braun and Clarke (2012, p. 297) describe thematic analysis as “a method for systematically identifying organising and offering insight into patterns of meaning (themes) across a dataset”. Hence the emphasis is on commonalities rather than individual and unique meanings or experiences. The aim of thematic analysis is to identify particular commonalities that help answer the research question/s. Braun and Clarke (2012) highlight two main advantages derived from thematic analysis: flexibility and accessibility. Flexibility lies in the fact that thematic analysis can be conducted in a range of ways including both inductive and deductive approaches and a retroductive/abductive approach. As Braun and Clarke (2012) point out, much thematic analysis combines elements of deduction and induction, whereby some themes are expected to be found in the data based on the literature or the theoretical framework, and others appear by themselves during the analysis. Accessibility is based on analysis and offering a step-by-step approach to coding and analysing qualitative data in a way that is systematic but not overly complex (Braun and Clarke, 2012). Thematic analysis adds rigour to qualitative analysis and ensures researchers avoid anecdotalism (Bryman, 2012).

Braun and Clarke (2006) proposed a six-phase approach as shown in Figure 3-2. The aim of this approach was to create a form of analysis that was “deliberative, reflective, and thorough” (Braun & Clarke, 2014. p.2).

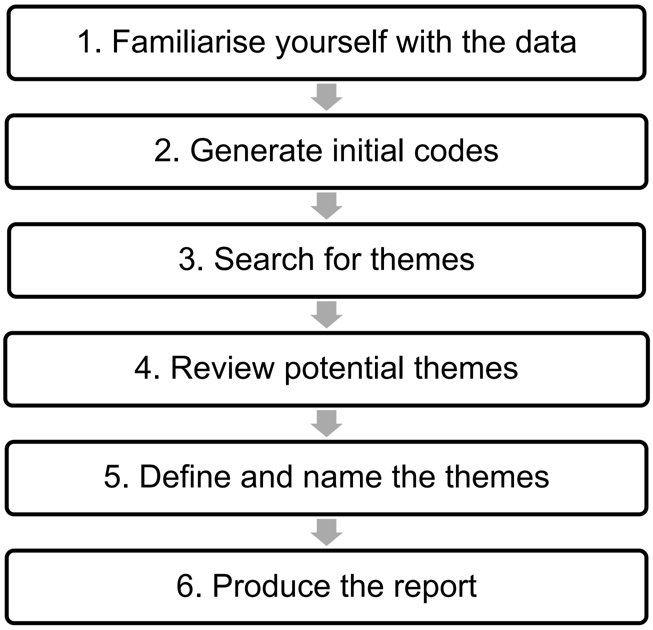


Figure 3-2: Braun and Clarke's six phase approach

Source: Braun and Clarke 2006.

Nowell et al. (2017) emphasise the need for qualitative researchers to make strenuous efforts to demonstrate that their data analysis was undertaken in a consistent, precise and exhaustive way. This can be achieved by providing sufficient detail to the reader so they can evaluate the credibility of the analytical methods and the findings. Part of this is maintaining an audit trail including transcripts and a reflexive journal (Nowell et al., 2017).

Thematic analysis has been viewed as insufficiently sophisticated for use in doctoral research. However, this critique has been countered by Braun and Clarke (2014) as overlooking the potential, flexibility and variability of the method. While they argue it can be used for interpretive analysis, it is particularly suited to descriptive realist analysis making it highly suited for use in the present study.

Qualitative researchers are further aided in their striving for systematicity by the availability of software applications to manage the analytical process. This option also makes an audit trail easier to maintain and may feature the use of screenshots. The generic term for these applications is computer-assisted qualitative data analysis software (CAQDAS). As qualitative data can often be highly voluminous, the use of such applications can be highly beneficial for organising the data, coding and retrieving them and arriving at a set of themes. The use of CAQDAS helps qualitative researchers counter the criticism for lack of transparency (Bryman, 2012), as these applications come with a range of tools and report generating functions. Furthermore, Silverman (1985) highlighted the potential for anecdotalism in qualitative research. For example, a researcher could select a quotation to support a finding when that extract is not especially representative of the data as a whole. CAQDAS offers the opportunity to count the number of similarly coded extracts. However, it is still the case that the researcher decides what and how to code. The way in which CAQDAS was used and the steps taken to ensure trustworthiness in the present research are further detailed in Chapter Four.

3.7 Normalization Process Theory

NPT was the theoretical lens chosen to explore the data for this thesis. The theory is primarily concerned with the work people do, interacting with each other and to make sense of processes that influence the normalisation of actions and behaviours. The theoretical lens was used to provide insight into the analysis and development of the study.

NPT was developed by Carl May and colleagues between 2000 and 2009 and has been defined as a ‘middle range theory’ (Boudon, 1991; Morrison & Mair, 2011). Davidoff et al. (2015) described middle range theories as frameworks for understanding problems and guiding the development of interventions in a practical sense.

NPT is a sociological theory that can be used to understand the dynamic and interactive processes between contexts, people and objects (McEvoy et al., 2014). It has also been known to bridge the translational gap (Morrison & Mair, 2011). NPT offers a method to conceptualise and provide description and explanation of the work of both individuals and groups. NPT addresses the social organisation of the work (implementation), making practice routines processes into everyday norms (embedding), and managing to sustain embedded practices in their social contexts (integration) (May & Finch, 2009). Importantly, NPT has also been used to better understand self-management processes (Gallacher et al., 2011; Gallacher et al., 2013; Kahn et al., 2015).

Much research has focused on outcomes of innovations (exploring their effects and measuring their impact). While this research sought to do this, the aim was to understand how these effects come into place and how social media influenced self-management, and NPT provided a framework to do this. NPT aids the understanding of how new ways of thinking, acting and organising can embed into healthcare systems or self-management activities. NPT focuses on the collective and individual work to achieve a set of goals. This framework was integral as the studies sought to understand the individual work (self-diagnosis, web searching, individually collecting information, individuals decision-making processes) and the collective work (participating in online health forums, peer-to-peer healthcare and engaging with HCPs) that people undertake to promote better self-management.

3.7.1 The core constructs of Normalization Process Theory

NPT seeks to normalise a set of practices and does so by four core constructs: coherence, cognitive participation, collective action and reflexive monitoring (May & Finch, 2009; May et al., 2015). A definition of each core construct can be found in Table 3-3. For NPT to be usable in this study, a considerable amount of interpretation work had to be undertaken for the constructs to be of relevance to the context of this study (May et al., 2015). In each of the following sub-sections, the constructs of NPT are defined as the academic literature presents them. The interpretation of those terms and how each construct is conceptualised for this PhD study is then mapped out under the heading. The constructs were relabelled to provide clarity of definition and meaning for the author and the reader. Coherence was interpreted as ‘sense-making work’, cognitive participation as ‘relationship work’, collective action as ‘enacting work’, and reflexive monitoring as ‘appraisal work’. Each of the four constructs, include four underlying working processes (May et al., 2009).

Table 3-3: Definition of Normalization Process Theory constructs

Coherence (CO) (Sense-making work)	**Cognitive Participation (CP) (Relationship work)**	**Collective Action (CA) (Enacting work)**	**Reflexive Monitoring (RM) (Appraisal work)**
The sense-making work that people do individually and collectively when they are faced with online self-diagnosis and seeking online health information.	The relational work that people do individually and collectively to build and sustain online health information seeking.	The operational work that people do by investing effort and time to engage in online self-diagnosis and seeking online health information and to use this information in consultations.	The appraisal work that people do when online self-diagnosing or seeking online health information that affects them and others around them.

3.7.1.1 Coherence (sense-making work)

The coherence construct (sense-making work) is a phase of planning work that is concerned with identifying what people do and what their approach is when trying to understand a new practice. Making sense of this new practice involves working individually and with other people. This construct is made up of four working mechanisms: differentiation, communal specification, individual specification and internalisation, each described in Table 3-4 (May & Finch, 2009).

Table 3-4: Coherence (sense-making work)

Differentiation (understanding the uniqueness of it)	**Communal Specification (collectively interpreting it)**
How a set of practices are different from each other.	*People working together to build a shared understanding of aims and benefits of a set of practices.*
Individual Specification (individually interpreting it)	**Internalization (coming to a conclusion)**
Sense-making also had an individual component. This relies on people doing things to help them develop an understanding of the responsibilities around a task and practices.	*Sense-making involves people understanding the benefits and values of a set of practices.*

Differentiation can be interpreted as how people gain an understanding of a new practice and how they differ from other sets of practices. Communal specification is the work people collectively do together to interpret the new practice and develop a shared understanding of the benefits. The third is individual specification – the work people do to interpret the new practice and develop an individual understanding of it. The fourth is internalization – this is the work people do to reach a conclusion about the practice and whether or not they will engage with it.

This PhD study is interested in how individuals make sense of online health information and how they interpret the information and its relevance into the context of their daily lives, and understanding if it adds any value.

3.7.1.2 Cognitive participation (relationship work)

The cognitive participation construct (relationship work) is a planning phase that identifies the work people do when trying to understand and organise themselves and others to embark upon a new practice, and the relational work that is undertaken to build this. Cognitive participation consists of four working processes: initiation, enrolment, legitimation, and activation (May & Finch, 2009). Each working process is described in Table 3-5.

Table 3-5: Cognitive participation (relationship work) – working process

Initiation (having skills to engage)	**Enrolment (organising people)**
Key participants driving a set of practices forward.	*Strategies used to engage with others in relation to tasks.*
Legitimation (validating the practice)	**Activation (defining actions)**
The belief that concerns or practices are correct.	*Defining actions, behaviours and procedures needed to sustain a practice and stay involved.*

The process that people go through to understand, think and organise themselves and others around a set of self-management practices can be defined into four mechanisms. Initiation is how people identify if they have the ability to undertake new practices. Enrolment is the work people do to engage themselves and others, so they are able to carry out the new practice. Legitimation is the work people do to come to an understanding that the new practice is correct and legitimate for them to carry out. Lastly, activation is the identification of what actions need to be considered in order to conduct the new practice.

This PhD study is interested in how online health information seeking and self-diagnosis can impact the patient-HCP relationship and collects patient/public and HCP perceptions of this practice.

3.7.1.3 Collective action (enacting work)

Collective action (enacting work) is the work that identifies what people do when enacting a practice. This type of action work can relate to the work undertaken to apply the intervention (the decision-making processes). This construct is made up of four working mechanisms: interactional workability, relational integration, skill set workability, and contextual integration (May & Finch, 2009). Each working mechanism is described in Table 3-6.

Table 3-6: Collective action (enacting work)

Interactional workability (doing the actions)	**Relational integration (working and developing trust with others)**
Interactional work people do with each other in consultations and other everyday settings.	*Communicating reliable knowledge about tasks to build accountability and maintain confidence.*
Skill set workability (dividing the tasks)	**Contextual integration (resource allocation)**
Understanding and/or learning about roles, tasks and responsibilities.	*Managing a set of practices through the allocation of different kinds of resources.*

The actions that people carry out to perform the work or self-management practice can be categorised into four mechanisms. Interactional workability is the action that is taken to perform the task. Relational integration involves working with others and developing trust. Skill set workability is the work undertaken to ensure the tasks are divided appropriately or the necessary skills are present or get developed to help achieve self-management tasks. Lastly, contextual integration is the resource allocation to conduct the task.

The current PhD study is interested in how and if people prepare (the prepared patient) for healthcare appointments and if so, what type of resources they decide to use, and the practical things they have to do.

3.7.1.4 Reflexive monitoring (appraisal work)

Reflexive monitoring (appraisal work) is a construct that focuses on the appraisal phase of work that monitor and evaluate the self-management work that needs to be done. The reflexive monitoring stage of the normalising process is enacted both individually and with others to help determine whether people will follow self-management advice or reconfigure it to make it workable, so that it fits into their everyday lives. Reflexive monitoring is made up of four working mechanisms: systemization, communal appraisal, individual appraisal, and reconfiguration (May & Finch, 2009). Each working mechanism is described in Table 3-7.

Table 3-7: Reflexive monitoring (appraisal work)

Systemization (collecting feedback)	**Communal appraisal (evaluation)**
Collecting information to determine how effective and useful it is (information could be collected in numerous ways).	*Working with others to determine and evaluate the worth of healthcare advice.*
Individual appraisal (individual evaluating it)	**Reconfiguration (Changing the method of how things are done)**
Working as individuals to appraise health advice.	*Appraisal work by individuals or groups can lead to redefining health care procedures or modifying practices.*

The process of assembling feedback on how the 'doing it' phase (collective action) was conducted, can be categorised into four mechanisms. Systemization involves collecting information and feedback about how the task was conducted in practice. Communal appraisal is working together with others to evaluate or judge the value of health care advice. Next is individual appraisal which is the individual work to evaluate the healthcare advice. Finally, reconfiguration is the practice people go through to process the information and feedback from the other three mechanisms, synthesise the information, make changes to the way they enact future practice, and decide whether they make the decision to continue to use these types of resources.

This PhD study is interested in how people use the information gained to make appropriate healthcare decisions, and if online health information is a practice they will continue to use or if their HCP is their main healthcare source.

3.7.2 How has Normalization Process Theory previously been used?

NPT has been described to have potential to promote the successful implementation of interventions that include interaction and engagement (Davidoff et al., 2015). It has also been used increasingly in recent years to help conceptualise and understand the self-management work associated with managing chronic illness (Gallacher et al., 2011; Gallacher et al., 2013; Kahn et al., 2015).

NPT is a tool that can be helpful at any stage of a research project such as informing the study design, to analysis and interpretation (May et al, 2015). A systematic review of studies using NPT concluded that researchers found the constructs useful across all aspects of their projects and to inform the study design, analysis and interpretation (McEvoy et al., 2014). The majority of papers included within the review by McEvoy et al. (2014) which included studies that have utilised NPT at any stage of the research process, identified NPT to be a beneficial framework at any stage of the research project lifecycle. It was also reported that NPT is a theoretical framework that facilitates understanding of experiences of healthcare work at an individual and organisational level. McEvoy et al. (2014) found eleven papers out of twenty that suggested NPT is useful for helping the development of clear recommendations for future implementation to be made. A more recent systematic review shared consistencies with McEvoy et al. (2014) in that it reported that researchers found NPT to be useful and were able to apply it to a wide range of interventions (May et al., 2018). It has been widely used to help understand studies of decision support and shared decision making in healthcare (Dikomitis et al., 2015; Kanagasundaram et al., 2016; Joseph-Williams et al., 2017) as well as E-Health and telemedicine (Blickem et al., 2014).

Finch et al. (2012) highlighted that although NPT provides a framework to explore processes of implementation, it cannot provide a definition of what ‘normalisation’ may look like within a given context. This is something that only those exploring the intervention or practice can define. Finch et al. (2012) also addresses the intense translational work that has to be carried out in order for the NPT constructs to be interpreted in relation to the context. Other reported critiques suggest difficulties in making sure the interpretations of the constructs coincide with the constructs in the original theory (Gunn et al., 2010; Franx et al., 2012; Atkins et al., 2011). There were reported tensions around using a predetermined conceptual framework and wanting to avoid ‘forcing data’ into predetermined codes or categories (MacFarlane & O’Reilly-de Brun, 2012). However, Mair et al. (2011) in a study of patient self-management, reported that only 6% of issues fell outside a NPT based coding framework.

NPT has been successfully used within various stages of the research process and has been utilised by more researchers as shown in the increased number of publications using the theoretical framework. It is generally used to illustrate issues around implementations of health interventions such as care for chronic conditions (Harris et al., 2017), and digital health interventions (Band et al., 2017). Overall, NPT provides a useful framework for understanding the processes that affect implementation, embedding and integration of new technologies into healthcare systems. The application of NPT to this PhD study is well suited as it offers a valuable set of conceptual tools for the understanding of implementation as a dynamic process (May et al., 2018), especially in relation to the integration of the use of online tools within self-management practices and the potential effects on subsequent patient – HCP interactions. The combination of all four NPT mechanisms, provide a conceptually rich framework to study in-depth, the behavioural implementation processes of various interventions (Dickinson et al., 2017; Gallacher et al., 2011).

NPT is considered a theory of action as it looks at what people do and not just what their beliefs or attitudes are towards a new intervention. NPT also captures what individuals are going to do as a result of a new intervention. May et al. (2009, p. 2) states that "to understand the embedding of a practice we must look at what people actually do and how they work". As this study considers the perceptions of two population groups (public and HCP's), and not only captures their individual beliefs but also their ways of working together and the implementation of the phenomena of online health information, NPT was considered the strongest framework to conceptualise this study. Additionally, NPT provides an explanatory purpose that other theories and frameworks do not, which is important when considering this to be a relatively new field of academic interest. Secondly, on a pragmatic basis, one of my supervisors had specialist knowledge and expertise of this theory. Finally, it has been highlighted in previous research that NPT can be successfully used at different stages in the life cycle of a research project, with particular value in qualitative and mixed methods research.

3.7.3 Considering other theories

The overarching aim of this study was to understand people's motivations for using the internet for health information and self-diagnosis, and how this impacts the patient-HCP relationship. An evaluation of other theories was considered before utilising NPT. Other theories such as the theory of planned behaviour and the patient health engagement model were considered in-depth. However, NPT was considered the strongest framework for this study, which is further explained in the following sections.

3.7.3.1 Theory of planned behaviour

The theory of planned behaviour is a psychological theory that was introduced to describe the behaviours through which people have the capability to exert self-control (Ajzen, 2011). The key component of this model is behavioural intentions. Theory of planned behaviour has been successfully used to predict various health behaviours and intentions such as smoking, drinking, breastfeeding and health services utilisation (Pourmand et al., 2020). The theory is made up of six constructs: 1) attitudes: the belief which informs the intention of behaviour, 2) behavioural intention: the motivational factors that influence behaviours, 3) subjective norms: the belief of approval or disapproval of the behaviour, 4) social norms: the codes of behaviour in groups of people, 5) perceived power: the perceived presences of factors that may cause barriers or facilitate the performance of a behaviour, 6) perceived behavioural control: the belief held of the factors that cause ease or difficulty for performing behaviours (Ajzen, 2011).

The theory of planned behaviour has a larger focus on how attitudes or intentions will affect work whereas, NPT relates to the work being done in interactions. Theories of intention support understanding of how people in collective activities frame behaviour. However, because such types of theories focus on individual process and group processes, they are less successful in the organisational processes distinguished by complexity and emergence, in which multiple variables act upon behaviour. In the context of studying use of online health forums for self-diagnosis, the focus was not just on the individual but how their online interactions with others influenced how they appraised advice and their actions. Using the NPT framework was a clear strength as it allowed examination of the actions of individuals and their engagement with others online.

3.7.3.2 The patient health engagement model

The patient health engagement model is based on evidence about patient experiences and preferences regarding their engagement in care. This model can be used by HCP’s and policy makers to help guide their interventions to engage patients in their care management (Graffigna & Barello, 2017). This model was considered as it could help inform HCPs about patient experiences online. However, this model does not grasp the complexity and dynamicity of psychological experiences of patient engagement (anxiety due to waiting for test results, understanding the effect of online health forums) in the way that the NPT framework allowed.

3.7.3.3 The health belief model

The health belief model was originally developed to understand why people decided upon using or not using preventive services. It has now evolved to address newer concerns in prevention and detection as well as lifestyle behaviours (Darvishpour et al., 2018). The health belief model is based upon people's beliefs about being at risk of a health problem or condition, and their perceptions of how to take action to avoid such problems. While the health belief model serves preventative matters, NPT was perceived as more useful in terms of this study due to the aims looking at more than just preventative matters, but also diagnostic, management and relationship factors that are of importance in a chronic illness context.

3.8 Chapter summary

The aim of this chapter was to present and discuss the options and choices evaluated in developing the research design used for this research into the phenomenon of online self-diagnosis and health information seeking. The chapter has set out and discussed the basis for the methodological choices made in designing the research through extensive synthesis of existing literature. The chapter highlighted critical realism as the paradigm for the research. The main choices regarding methods were primarily concerned whether to select quantitative, qualitative or mixed methods. The chapter set out why mixed methods leading into qualitative methods were preferred and why a qualitative descriptive research design was selected. Additional choices were reactive, arising from the COVID-19 pandemic and its consequences for fieldwork. Specifically, face-to-face interviews and focus groups were dropped, and the main method of data collection was decided to be online interviewing. As a data collection method, the literature suggests that conducting interviews online, particularly synchronously, is a viable and valuable option. The reason for choosing a semi-structured format was also explained. The chapter discussed thematic analysis and in particular Braun and Clarke's (2006) six-step process that was adopted to add transparency and rigour to the analytical process. Finally, the theoretical framework underpinning this study, NPT, was introduced, critiqued and its utilisation in other research described. The next chapter presents how the research was operationalised, describing in detail how the researcher choices made in this chapter were brought to reality.

Chapter 4 - Methods

4.1 Introduction

While the previous chapter mainly addressed the “why?” questions for the current research and discussed the justifications for the main methodological choices made, this chapter explains the “Where?” “What?” and “How?”. It provides a detailed account of the research methods employed and explains how the research was operationalised. Before describing the individual phases of the research, the nature of the sequential research and the use of triangulation to improve the quality of the research is explained. After this, the principle of public and patient involvement (PPI) in research and how it was applied to this research is discussed.

PPI has been integral and valuable to the design of each study within this thesis. Additionally, I am part of my supervisor, Professor Bridget Johnston’s PPI research group. PPI is central to all PhD’s in our research group in order to promote public participation in research in nursing and healthcare at the University of Glasgow. For this research, I recruited two PPI participants.

The research comprised three distinct phases each using different methods and research processes, and the sequential design of the research is reflected in the organisation of this chapter. After each research phase is described and discussed in terms of the methods used, the ethical considerations of the research as a whole are discussed and then the chapter is briefly summarised.

4.2 Sequential design and triangulation

The methods and processes described in this chapter were deployed sequentially between October 2017 and February 2021. Sequential research has the advantage of each phase informing the conduct of the next and enabling adjustments to be made. Against this, a sequential design may take longer to complete and requires review at the end of each phase to verify the most appropriate way to proceed (Creswell, 2015; Ivankova et al., 2006). The first phase comprised a mixed methods systematic literature review that provided the research with a detailed view of what was already known about the phenomenon of interest and exposed the gaps in this knowledge. The second phase was a thematic analysis of online heart failure forums, divided into two parts (I) an analysis of user posts and (II) an analysis of responses to these posts. The third phase was an interview study which was also divided into two parts: (I) interviews with a sample of patients as online health information seekers and (II) HCPs. The sequential design is summarised in Figure 4-1.

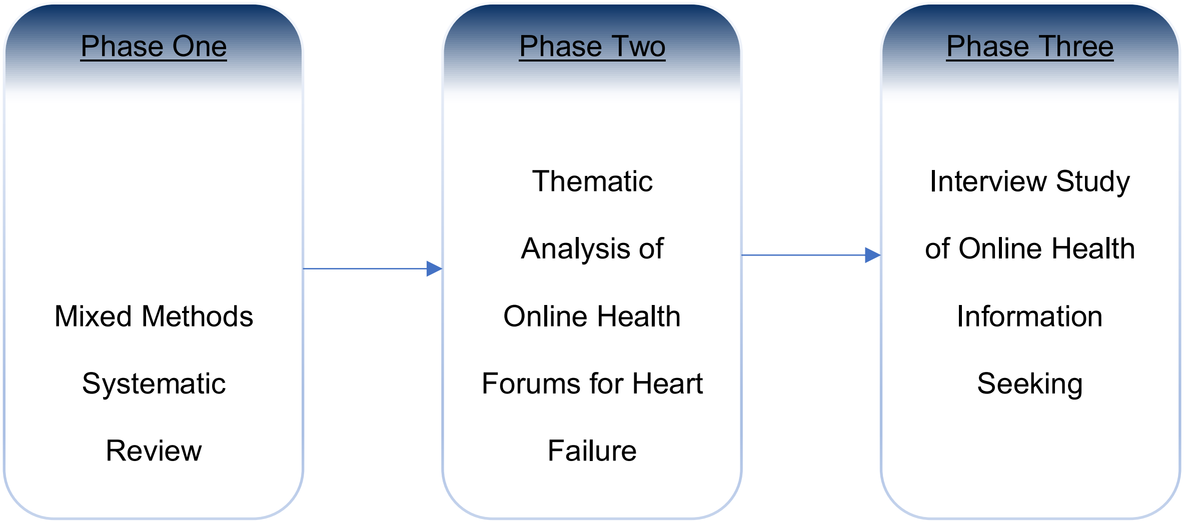


Figure 4-1: The sequential research design

To maximise the quality and validity of the research, the research built triangulation into the research design. Bryman (2008) described triangulation in research as “the use of more than one method or source of data… so that findings may be cross-checked” (p.700). This technique is recognised as a way to add depth to a piece of research as well as rigour and complexity (Denzin, 2012). Triangulation can occur at a number of levels such as data sources, data collection sites and data types. The triangulation used in the present study is illustrated in Figure 4-2.

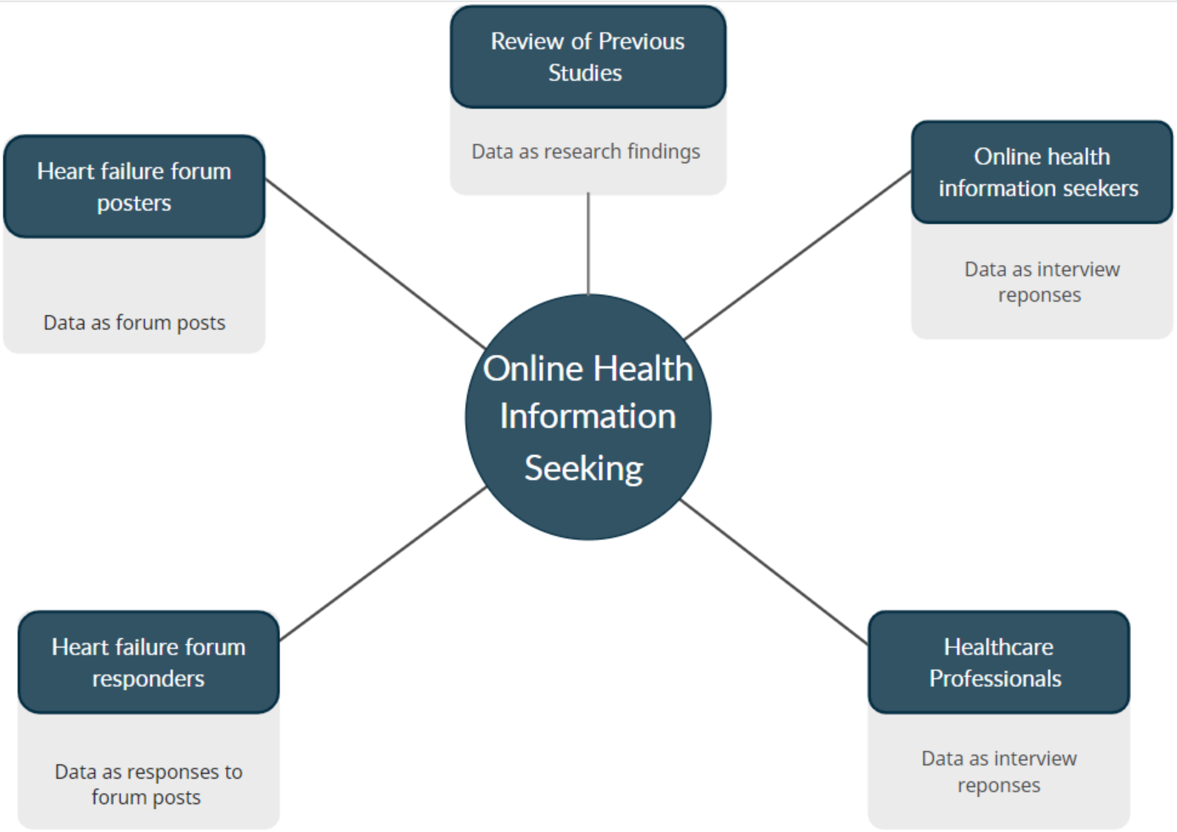


Figure 4-2: Triangulation of data sources and types

4.3 Patient and public involvement

Guiding the research and the methods adopted was the principle of PPI. Contributions from meetings with a PPI group helped to inform the protocols and study designs which were then lay reviewed by members of this group. This degree of participation and involvement aims to ensure the results and recommendations are relevant and of purpose to the target population.

Within this research project, two members of the public helped to inform the design of the studies included. They provided their input for what aims they believed the study should achieve and the benefits participants will gain from this study. They also helped to advise the layout and format of documents such as the participant information sheet and confirmed the information was understandable and in lay language.

This section will discuss the recruitment of PPI representatives, introduce both individuals' stories, and how they helped to inform the designs and contributed to the studies reported herein. Beverley and Tommy were part of the PPI group for this PhD and have both given consent to be named and have their stories discussed within this thesis. Please see Appendix 1 for evidence of consent.

4.3.1 Recruitment of PPI representatives

In order to recruit PPI representatives, an understanding of the role, the contribution that would be expected of them and the process as a whole had to be developed, along with an understanding of how to organise and structure meetings and develop a relationship with a PPI representative.

I underwent training for the involving of PPI representatives in research. This included PPI and engagement training workshops. The workshops addressed ways of working with PPI advisors for research; challenges and how to overcome them; resources and where to find help and support; how to write a lay summary and patient information sheet; and how to keep your research engaged with the public. Opportunities were available to help facilitate and organise PPI events as well as present at them, which allowed for this research to be discussed with members of the public and practice not only writing, but also verbally communicating with the public in an appropriately levelled language.

A series of steps were taken for the development of the recruitment process. Criteria were developed to reach a target group of people who may be interested. A flyer was created which outlined what the role was and the subject area (see Appendix 2). Two questions outlining key topic areas were asked on the flyer:

1. Have you used the internet to self-diagnose or look up health information?

2. Have you used the internet to self-diagnose or look up health information for heart failure/heart conditions?

Highlighting the general use of the internet for health information, as well as specifying a potential target group of people with, or searching for information on, symptoms of heart failure, allowed a wider audience to be reached. Potential respondents were informed that they may be involved in creating recruitment strategies; helping to conduct interviews; reviewing writing styles; attending conferences; delivering ideas and opinions to help with research projects; and joining in with other research public involvement advisors. The flyer was posted on Twitter and shared on the Chest, Heart and Stroke Scotland website within the research opportunities section.

Beverley was recruited from Twitter and met the eligibility criteria to contribute towards this PhD project as a PPI. Beverley had been participating in a Twitter takeover on the NHS England page sharing her story, which brought us into contact. PPI meetings with Beverley were conducted over the telephone due to being unable to meet face-to-face because of distance.

Tommy was recruited at a digital health conference I had attended in Glasgow where he was presenting his experiences as a carer and discussing how online blogging had positively impacted his experience. Tommy lives in Glasgow therefore we were able to have face-to-face meetings before COVID-19. However, due to the pandemic, the method of contact has more recently been through Zoom (Zoom, 2016).

4.3.2 Beverley's story

Beverley is passionate about keeping fit and healthy. She is an experienced runner and has participated in nine London marathons. Six years ago, Beverley was running in the mountains of Portugal when she came to an abrupt halt and felt excruciating pains in her chest. Upon arrival in the UK, she booked an appointment with her GP. The GP performed tests such as an electrocardiography (ECG) and found abnormalities. She was advised to visit the emergency department to be reviewed by a cardiologist.

Beverley arrived at the emergency department and was assessed by a cardiologist. They diagnosed her with a twisted oesophagus, and she was later discharged. Upon discharge, Beverley went back to her daily routine. However, shortly after she left, she received seven missed calls from the hospital. When she returned the call, it was the junior doctor who was working alongside the cardiologist trying to reach her to ask her to return to the hospital immediately as he did not feel comfortable with her discharge and had received a second opinion on her ECG from another cardiologist.

Upon return to the hospital, Beverley was admitted straight to the Critical Care Unit and was in the catheterisation laboratory the next morning after being told her main left artery had a 90-95% block which led her to having a percutaneous coronary intervention (angioplasty with stent).

Following her intervention, Beverley was diagnosed with acute coronary syndrome. She did not receive a follow-up appointment until six months after her diagnosis with her cardiologist. She was given information leaflets that she did not feel were patient friendly, and felt she was left to her own resources for further education about her newly diagnosed condition. For the first two weeks following her diagnosis, she reported feeling down and lost. However, her love for exercise helped her maintain an active lifestyle and healthy diet. Beverley believes that more people should adopt a healthier and active lifestyle pre- or post-diagnosis, to maintain a healthy heart.

Beverley has set up a Twitter page which engages many peers, heart specialist nurses and cardiologists and posts regularly about up-to-date research; exercise and diet intake; and the benefits of exercise and diet for heart health. Beverley has made many connections through the power of social media and shares her story to help others.

4.3.2.1 Beverley's contribution to this research

Beverley helped to inform the design of this research by sharing her experiences and opinions about the research aims and objectives. Beverley and I have had phone conversations to discuss updates relevant to the research and to Beverley's healthcare experiences.

Beverley reviewed the ethics applications and the design of the different phases of the research. She also helped to inform the interview schedule for the final phase. This ensured the researcher was asking questions that were informed by a person with real life experiences of heart conditions and online health information. In Beverley's personal experience, she listed what she saw as the main benefits of and reasons for seeking online health information. These were described to me as:

- To gain a better understanding of her health.
- "Healthcare professionals cannot do everything for you".
- To be able to understand and gain more knowledge on the condition she was facing.
- To join and utilise closed support groups (e.g., on Facebook).

Based on her experiences, Beverley felt that the information flow from HCPs to patients could be improved. She was sent home with only leaflets for her heart diagnosis and felt these were insufficient and left her feeling lost at that crucial time after the diagnosis.

Beverley felt it could be beneficial if there were online sources given to her at the time of diagnosis, as well as a patient representative who lives with the condition, to talk to her and to give her answers that are based upon real life experiences.

4.3.3 Tommy's story

Tommy was a carer for his mother, Joan. Prior to caring, Tommy had worked in music for 25 years and had travelled the world. Tommy had planned a short visit home to see his mother, however, when there she became quite poorly. The short two-month trip became more than one year as his mother was diagnosed with vascular dementia. Tommy cared full-time for his mother for what would become almost six years. During this time, Tommy began to notice changes within their lives and said they both felt scared, lost and alone.

Tommy wanted to understand how other people managed. He felt that if he knew how other people got through these experiences, he could do the same. He sought information online which led to Tommy's idea of beginning a blog. He began writing about his experiences and felt the blog was therapeutic and wanted people to hear how he felt through his writing, as he did not feel he was being heard by HCP's.

At some points, Tommy felt like he was the only carer in the world and his mother was the only person with dementia. However, when he started his blog, people from all parts of the world started sharing their stories with him. People wrote to him saying they did not feel judged online, and they just want someone to listen to their story. Tommy realised that although he felt alone in his experience, the internet showed him he was not alone in how he felt, and his experiences related to many others who shared what he was going through.

One of Tommy's realisations from his experience as a carer was that in the healthcare system, many people listened with an intent to reply instead of listening with an intention to listen. Additionally, Tommy found that some peers felt confiding in a HCP to be daunting as their feelings would become a permanent record. However, using the internet was a platform that could stay anonymous and non-judgemental.

Searching for support in the healthcare system, was something Tommy saw as taking months. He felt by the time support was put in place through the healthcare system, it did not add the same value as it would if it happened earlier. However, being able to use the internet to connect with others provided quick access and allowed Tommy to have an outlet and engage in peer-to-peer support.

4.3.3.1 Tommy's contribution to this research

Tommy helped to inform the design of this research by sharing his experiences and opinions. We regularly discussed updates relevant to the research and Tommy's healthcare experiences. Tommy helped to inform the study aims and objectives, discussed the findings of the different phases as they were completed, helped to inform the interview questions, and reviewed the patient information sheet, consent form and privacy notice before they were submitted to the research ethics committee at the University of Glasgow.

Tommy felt that a photograph of the researcher should be included on the participant information sheet to allow potential participants to feel more connected to the study and to adopt a more personalised approach. Tommy also advised me to ask participants if they would like to be kept up to date with the study's findings. This, he commented, would help the participant feel assured there would be a follow-up to their contribution.

Based on Tommy's personal experiences, he listed the conclusions he had drawn, and the potential roles online health information could play:

- Many people sharing similar experiences also share similar emotions. This could be studied more to improve online and offline healthcare services.
- Lack of education for the public regarding long-term conditions. There should be online resources in place to educate families when a relative is diagnosed in order to better prepare themselves.
- There are a lot of helpful services that people do not know about unless they search online themselves.
- There should be a bigger role for PPI for people with long-term conditions whether it be online or in hospital settings.
- Online peer-to-peer support is helpful.
- Better education of the public about the responsibilities of each healthcare role in the healthcare system through online sources.
- Opportunities are missed for providing support within the healthcare system. Better use could be made of online resources for public support.

- Carers have the right to a life outside caring. Online support can allow people to recover quicker.

4.4 Phase one: A mixed methods systematic review

4.4.1 Introduction

A mixed methods systematic review of existing literature provides in-depth information about the type of research that has previously been conducted in order to determine what is known on the topic and help identify research gaps (Lizarondo et al., 2020). The core intention is to combine qualitative and quantitative data to create a depth of understanding that can confirm or dispute evidence and fundamentally answer the research questions under consideration (Lizarondo et al., 2020). Therefore, it is an invaluable activity prior to embarking upon new primary research.

This mixed method systematic review was developed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) quality requirements. The protocol is registered on PROSPERO, the International Prospective Register of Systematic Reviews (CRD42018084230). PROSPERO records key features from the review protocol and is maintained as a permanent record (see Appendix 3). It is advised that systematic reviews are registered at the protocol stage in order to avoid unplanned duplication and to allow comparison of reported review methods with what was planned in the protocol (PROSPERO, 2018).

The research questions for the present research were first presented in Chapter One. Of these, the following questions are addressed by this phase of the research:

RQ1. *How does online health information seeking affect the patient-HCP relationship and medical authority?*

RQ2. *How do HCPs perceive patients use of online health information and its effect on the patient-HCP relationship?*

RQ3. *How do public/patients perceive the use of online health information and its effect on the patient-HCP relationship?*

4.4.2 Search strategy

The systematic literature search was conducted using five leading academic databases: MEDLINE, EMBASE, CINAHL, ACM and Scopus. The decision to use multiple databases followed the desire to ensure as comprehensive a review as possible. The databases can be briefly summarised as follows:

- MEDLINE is a medical and biomedicine database which includes medical subject headings (MeSH terms).

- EMBASE is an Elsevier database that is also aimed at HCP's. It covers all of MEDLINE plus an extra 2000 titles with inclusion of drug & pharmacy journals. However, instead of MeSH, EMBASE uses a guided mapping of keywords to Emtree.

- CINAHL is a database aimed for the use of nurses, students and allied health professionals. Since the study has a nursing approach, this database was deemed appropriate. CINAHL has its own explosion headings.

- Scopus is known to be a more multi-disciplinary database offering multiple views of the health care area and is also the largest database of peer-reviewed literature. This database does not allow for any explosion terms and only keywords were used in the search.

- The ACM Digital Library database is the most comprehensive database of computing and information technology. This was deemed appropriate to gather research within the health technology fields.

Filters were applied using the advanced search functions of the respective databases:

- Year of Publication: 2007 to 2018
- Language: English
- Subjects: Human
- Full text available

The year 2007 to the then present year of 2018 was considered an appropriate timeframe as it was a period when high levels of internet connectivity were prevalent and new devices were being acquired by the public in large volumes. In particular, 2007 was the year that the first iPhone was released (Apple, 2007). The English language was chosen as there was no funding to support translation. Additionally, limiting results to human subjects prevented irrelevant results. The full text would need to be available for subsequent screening, so the automated 'full text' option was also applied.

The search strategies were conducted using database-specific controlled vocabularies and free text terms. The key search terms included 'information seeking behaviour', 'online self-diagnosis', 'internet', 'professional-patient relations' and 'mobile app'. There is not one universal term to describe internet use for health information. Therefore, it was important to search for both self-diagnosis and information seeking behaviour terms, as they can both indicate different types of internet use. Information seeking may be someone that is already diagnosed but wants to know more information about a specific condition. Self-diagnosis is seeking either the initial diagnosis, or a different diagnosis. These different search terms can show a variety of information platforms being used.

The full MEDLINE search strategy can be found in Appendix 4. Figure 4-3 shows the number of search results for each database. Endnote (Endnote, 2018) was used as a reference manager and all 7026 references were downloaded onto this software. Endnote was used to de-duplicate the references which left a total of 6109 references.

Figure 4-3: Literature databases and total number of relevant references

4.4.2.1 Updating the systematic review

The systematic review was published in 2020 (Farnood et al., 2020), and had search dates running from April 2007 to April 2018. Therefore, an update of this systematic review was conducted in May 2021 and included search dates from 2018-2021. Guidance was taken from Garner et al (2016) who published a consensus and checklist based upon the COCHRANE guidelines of how to efficiently update a systematic review.

Seven new articles were found in the updated search and are included in the data extraction and socio-demographic tables (Appendix 5-8) and have been quality appraised using the mixed method appraisal tool (Appendix 9). The results in Chapter Five will report the findings of the original and updated searches together.

4.4.3 Eligibility criteria

In addition to the above stated automated filters, further eligibility criteria were applied manually to the search results (Table 4-1). These criteria are applied to ensure that the review is sufficiently focussed and the number of articles requiring full text reading is manageable with the resources available. Four main criteria were identified: type of studies, type of research subjects, the topic focus, and the setting. They are described in the following sections.

4.4.3.1 Types of study

The type of study relates to the field of study and the research methods used. As this was a mixed methods systematic review, the aim was to ensure all potential eligible studies were included and therefore both studies that reported primary data (qualitative and quantitative studies), and studies using any form of qualitative, quantitative or mixed methods were included. A mixed method systematic review allowed the questions to be addressed by including forms of evidence from different types of research, allowing for expansion of the findings (Harden, 2010). In effect, this tackled gaps in the research by examining both qualitative and quantitative methods to better inform the next studies.

4.4.3.2 Types of participants

Studies stating their participants were adults (over the age of 18) were included. These adults could be members of the public, patients, or HCP’s.

4.4.3.3 Topic

The topics of eligible studies had to be related to online self-diagnosis, online health information seeking or internet health. Any physical health conditions were deemed eligible to be included. Topics that discussed any level of the diagnostic process were eligible (pre-diagnosis, post diagnosis and treatment). Perceptions of patients, public and HCPs were included, as well as patients' and public use of online health forums to communicate with peers.

4.4.3.4 Setting

Since online self-diagnosing can take place in any setting that has internet access or service areas, all normal type settings are deemed appropriate. The clinical setting was only focused in primary care and otherwise any setting outside the clinical area.

4.4.4 Exclusion criteria

In addition to the automated filters (language, publication data, human subjects), studies published before 2007 were excluded.

Studies that were grey literature/not published in a peer reviewed journal, dissertations/theses, secondary data analyses, published abstracts, conference proceedings, commentary articles written to propose opinions and letters, or editorials, were all excluded from the review. Studies that included participants under the age of 18 were also excluded.

Mental health was not eligible for this review as the focus was on physical health conditions. Additionally, cancer, plastic surgery and maternal health were excluded for the purposes of the review as these are large specialty areas. As a nurse, I have not specialised in either mental health, midwifery or plastic surgery, therefore it seemed appropriate to focus only on physical health conditions. Cancer research is a large specialty area where a vast amount of research has already taken place. Cancer specialities seemed appropriate if the focus were only on cancer as the specialty is so large. However, after literature searching and with the knowledge that there is already a large body of research within the cancer field (Marcu et al, 2018; Yavan, 2015; Xiao et al, 2014; Pandey et al, 2013; Klemm et al, 2003; Sullivan, 2003), the aim shifted to cover the broadest swathe of physical health conditions.

This helped to determine which physical health conditions were and were not as heavily researched. Table 4-1 presents the full inclusion and exclusion criteria.

Table 4-1:Inclusion and exclusion criteria

Study type	• Publication date from 2007 – 2018. • English language only. • Studies that report primary data (qualitative and quantitative studies), Studies can use any form of qualitative or quantitative methods.	Interest was in papers ranging from the years of 2007-2018 as the first Apple iPhone was created in 2007 (updated search considered publications from the years of 2018-2021). As this is a mixed method systematic review, the inclusion of studies that report primary data and use any form of qualitative or quantitative methods were considered appropriate for eligibility. This is to offer a broader scope in answering the research questions, and a better representation of the range of research that has already been undertaken. Study types that were grey literature/ not published in a peer review journal, dissertations/thesis, secondary data analysis, published abstracts, conference proceedings, commentary articles written to propose opinions and

		letters, or editorials were excluded from the review.
Participants	- Any individual (adult) over the age of 18. This includes patients, the public and HCP's.	This study will only be reviewing adults aged 18 and over in order to maintain a generational research focus.
Topic	- Any physical health conditions. - Must be in relation to online self-diagnosing and health information seeking on the internet. - Can include any level of the diagnosis process - diagnosis, processing and treatment options. Can include the perceptions of the public and HCP's on the topic. - Patient's use of online health forums to communicate health information with other patients.	There is currently a variety of health conditions being searched for on the internet, so this review aims to explore a range of different medical searches instead of specific conditions. Online health forums are a commonly used medical resource, therefore were included for eligibility. Mental health was not eligible as this is a broad area and the focus was only on physical health conditions. Cancer and maternal health were excluded as these are both large specialty areas, but all other physical health conditions were included.
Setting	- Any 'normal' health care setting (community, primary care clinics, home, online, education facilities).	Online self-diagnosing can take place in any setting that has internet access or service areas; therefore, all normal type settings are deemed appropriate. The clinical setting was only focused in primary care and otherwise

		any setting outside the clinical area.

4.4.5 Screening process

The screening phase was conducted on the systematic review software, DistillerSR (Distiller, 2018). DistillerSR is designed to efficiently manage the screening and data extraction processes for systematic reviews (DistillerSR, 2018). After de-duplication, all the references were downloaded onto DistillerSR for screening. Screening was conducted in three phases: title, abstract and full text.

For the title screening, the following question was addressed: ‘Is this article about online self-diagnosis and information seeking for any physical health condition?’ Applying this broad test to the titles of the search results reduced the number from 6109 to 708 which were carried forward for abstract screening.

Abstracts were scanned, read and two questions were applied to test for eligibility. ‘Does the article meet the inclusion/exclusion criteria?’ and ‘will the article help the researcher address the research questions?’ As a result of this phase 287 articles were progressed to the full text screening phase.

For phase three of the screening process, all of the full text articles were read and, where applicable, labelled with reasons for exclusion. This phase sought to verify the questions asked in the previous phase and acted as a further eligibility check.

The reasons for exclusion of full text articles were the following: unable to gain access to the article (n=9); published before 2007 (n=2); wrong setting (n=19); wrong study design (not peer reviewed) (n=55); not enough relevance to the research questions (n=76); parents seeking information about their children (n=7); articles related to the topic of cancer (n=52); HCP’s seeking online health information (n=16); complementary and alternative medicine (n=1); surgery/plastics (n=9); not about internet only (n=3); pregnancy/maternal/midwifery (n=7); and mental health topic areas (n=8).

Additionally, backward and forward chaining was implemented in order to ensure no key articles had been missed. Backward chaining involves examining the references cited within an article (Al-Ajlan, 2015). Forward chaining is the identification of articles that cite an original article or work after it has been published, focusing on publications developed after an article's publication (Al-Ajlan, 2015). This technique was implemented after the final number of studies were found in the original searches. Two further papers met the eligibility criteria to be included in the review which brought the final number of included studies to 25.

This phase sought to verify the questions asked in the previous phases and acted as a further eligibility check. The PRISMA based screening process is summarised in Figure 4-4.

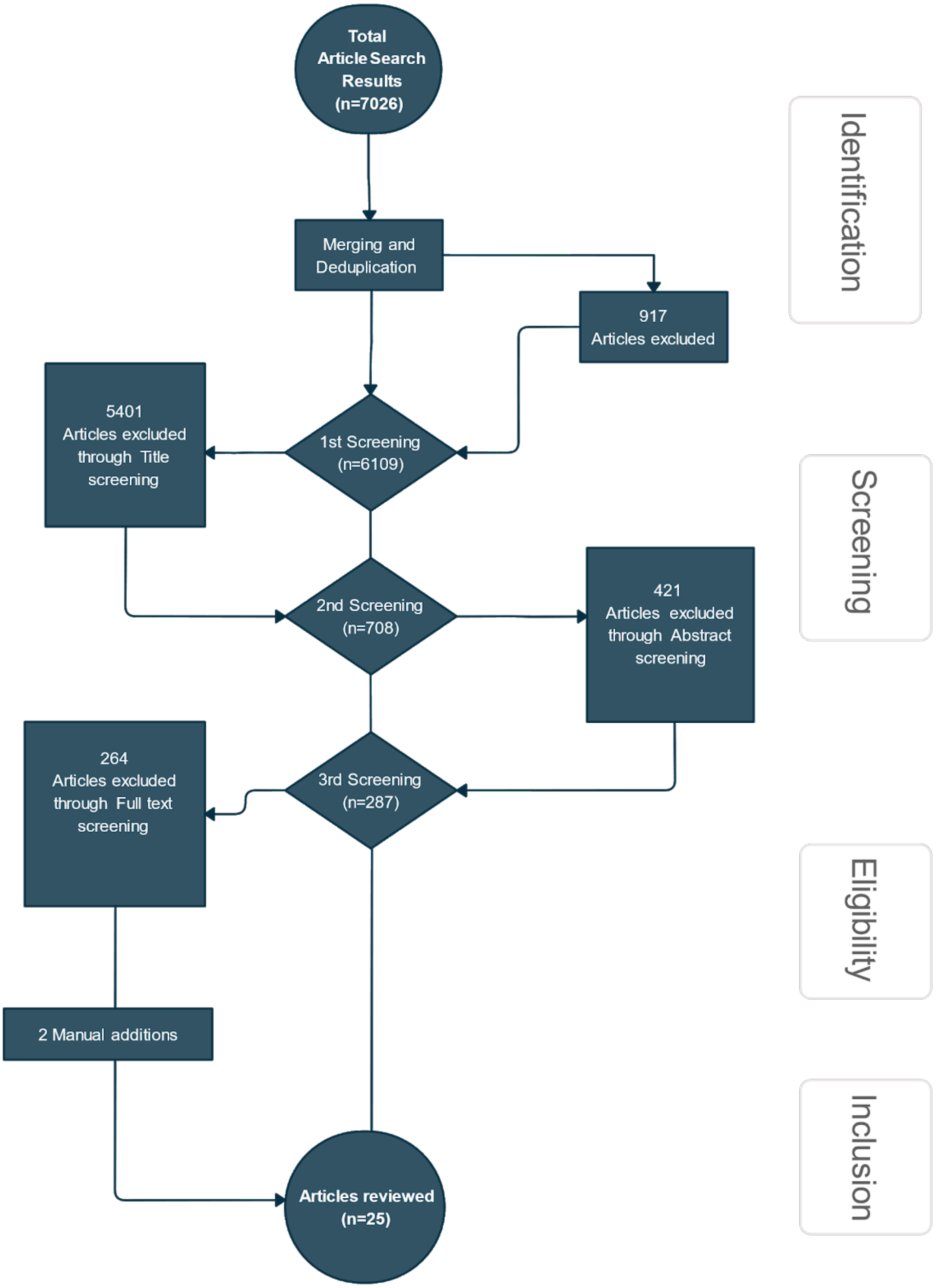


Figure 4-4: PRISMA chart of search and screen process

4.4.6 Data extraction

A standardised data extraction form adapted from Johnston et al (2009) was used to collect study characteristics for papers that met the eligibility criteria. Data extraction tables were developed to pull key pieces of information from the articles. The following headings were included in the data extraction tables; author/year/country; aims of study; methods & quality; participants; settings; and key findings. Three separate tables were made for qualitative, quantitative, and mixed methods (see Appendix 5-7). In total, there were sixteen qualitative, eight quantitative and one mixed methods paper. In the updated search, two further qualitative papers were eligible to be included and five quantitative papers.

A socio-demographic table was also developed to identify the characteristics of participants. Within this table, the following headings were included: author/year/country; number of participants; type of participants; gender; age; ethnicity; and socio-economic status (see Appendix 8).

If there was any uncertainty over the content and applicability of the data for the review, this was resolved through discussion within the team.

4.4.7 Quality appraisal

Quality appraisal is the process of systematically examining research to judge its trustworthiness, value and relevance (Burls, 2014). As this is a mixed method systematic review, a quality appraisal tool was required that could assess a diverse range of articles in a systematic way.

Many tools, such as the critical appraisal skills programme (CASP, 2018), were evaluated. However, the mixed methods appraisal tool (Pluye et al., 2009) was chosen because it is designed specifically for mixed method studies and appraises qualitative, quantitative, mixed methods, and other types of empirical studies (Hong et al., 2018), which fits the criteria for this review and had been successfully used in previous literature (Simblett et al., 2018; Klassen et al., 2018; Pluye et al., 2019). The tool is split into two sections: screening questions and the explanation phase. The mixed method appraisal tool discourages the use of a scoring system and instead offers a detailed presentation of the ratings to provide a better explanation of the quality of the included studies (Hong et al., 2018). A spreadsheet template was used on Microsoft Excel (Microsoft Corporation, 2018) with a ‘yes’ or ‘no’ answer system in order to gain a score percentage, followed by an explanation column to justify the quality assessment score. Papers were graded 1–5 and classed as low, medium, or high quality (see Appendix 9).

Discussions were engaged over any discrepancies, with a record kept of how the decisions were reached. All articles that met the study inclusion criteria were kept even if they were found to be methodologically weak based on the quality assessment, as they still have the potential to provide new and valuable insights in a field where the literature is relatively sparse. The quality assessment of included studies can be found in Appendix 9.

4.4.8 Data analysis

The findings of qualitative and quantitative studies were tabulated separately. The included studies were read, and a thematic analysis using the Braun and Clarke (2012) method was undertaken to establish a list of themes and sub-themes. Coding clinics were held to refine the themes identified. Each item of extracted data was coded independently through thematic analysis and reviewed by two researchers. Themes were mapped onto the constructs of the NPT framework.

Chapter Five will include the full findings of the mixed methods systematic review. The next section will describe the methods utilised for analysing heart failure online health forums.

4.5 Phase two – part I and II: Heart failure online health forum analysis (posts and responses)

4.5.1 Introduction

These qualitative descriptive studies examined online health forums for those with heart failure or looking to understand whether their symptoms might suggest a diagnosis of heart failure. In part one, the posts were analysed to understand the types of information people were seeking. In part two, peer responses to discussion posts were analysed, to understand the quality and types of information provided. An inductive version of thematic analysis

(Braun & Clarke, 2012) was utilised, and themes were then mapped onto the core constructs of the NPT framework. The responses were assessed for quality against the National Institute for Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) guidelines to determine whether they were evidence based or not.

4.5.2 Discussion forum search strategy

Popular internet search engines (Google, Yahoo and Bing) were used to identify online health and discussion forums. These three search engines were selected as they are reported to be the top three most used search engines with more than 95% of all searches made on them (Chris, 2019).

4.5.3 Eligibility criteria

The following inclusion/exclusion criteria (Table 4-2) were used to identify online health forums and their content for inclusion:

Table 4-2: Inclusion and exclusion criteria

Inclusion	Exclusion
• Google, Yahoo and Bing search engines. • Only the first two result pages of each search engine will be analysed. • Selected forums must be about heart failure. Can be about 'heart diseases', if it includes posts on heart failure. • Discussion posts will only be analysed from the year 2016 to 2019. This year was chosen as the Scottish Intercollegiate Guide Network (SIGN) guidelines for heart failure were last updated in 2016.	• No other search engines other than Google, Yahoo and Bing, as these were the three most popular search engines. • No pages to be searched further than the first two result pages due to the reported rarity that users would search beyond the second page. • Forums that do not include discussion about heart failure. • No posts will be screened before 2016. • Websites with forums whose purpose of discussion is not health related will be excluded and if they do not allow

	input from public/patients and caregivers (for instance expert opinion or professional advice websites online). - Any discussion posts that declare the individual is under the age of 18 will be excluded.

The main search terms used were ‘heart failure online support forums’ and ‘online health discussion forums for heart failure’. The search engines were tested with different terms to see what returned the most relevant and frequent results describing online health forums, and these two terms were most prevalent.

The first two pages of search results were screened as it was reported that the typical internet user did not browse further than the second page (Jacobson, 2015). Websites were selected according to the name, content and recent activity. Figure 4-5 presents the search engine results.

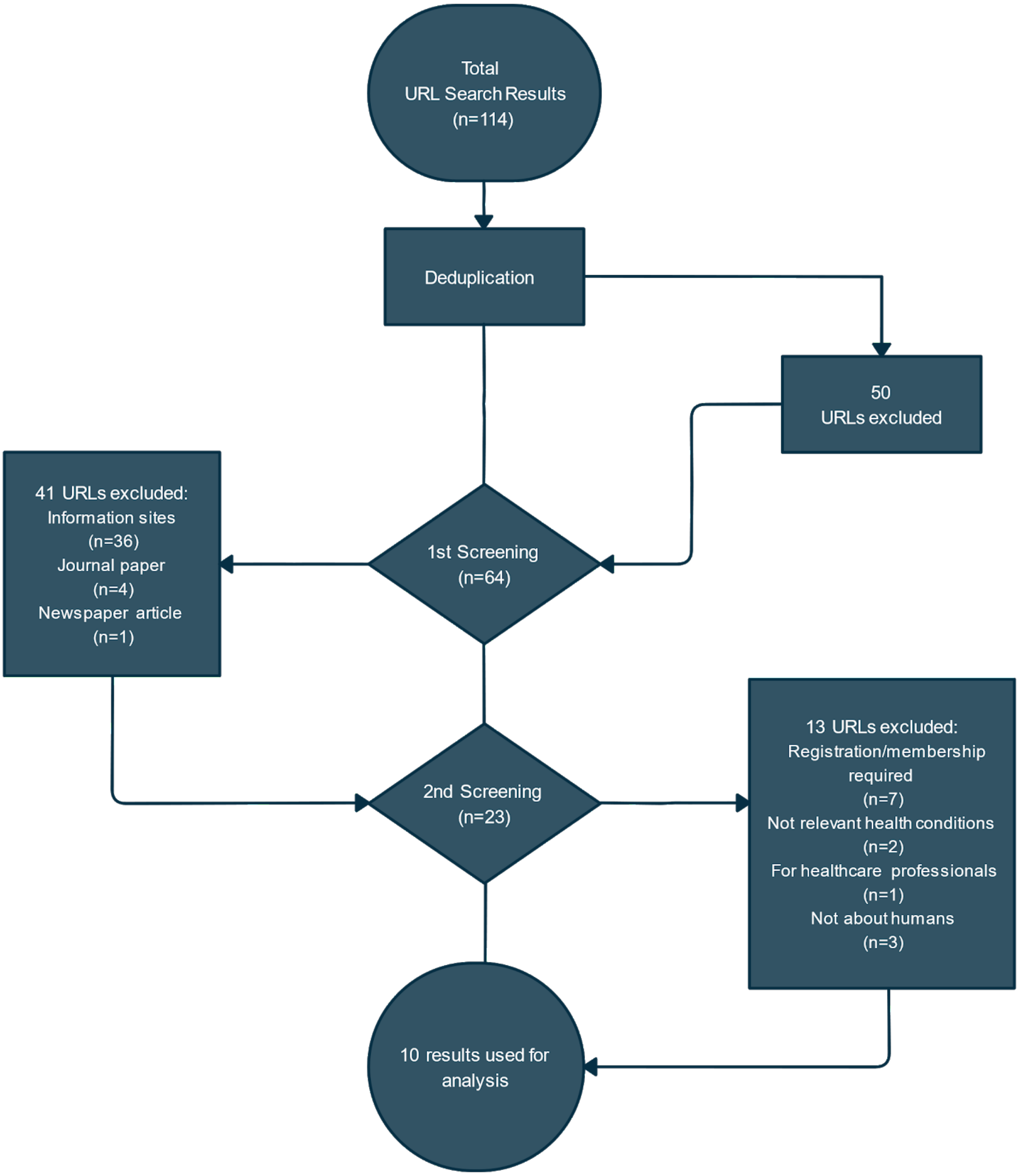


Figure 4-5: Retrieval and screening of search results

The selected forums were required to have a section about heart failure or heart diseases. If there was only a section about heart diseases, it was still screened but only for posts discussing heart failure. Websites were excluded if the purpose of the discussion forum was not health related and if they did not allow input from both patients and caregivers. They were also excluded if there were no comments about heart failure since 2016. For all selected online health forum websites, posts were screened from the year 2016 to 2019.

The last update on the heart failure SIGN guidelines was in 2016 (SIGN, 2016) therefore, screening was from that year.

There was no interaction or participation from the researcher on the forums. Only patient and public discussion forums were included as people's use of the internet was being examined as opposed to interactions involving HCPs. Purposive sampling (Sharma, 2017) was conducted in which posts were browsed by subject title, date and relevancy to heart failure. If they met these criteria, they were collected for analysis.

4.5.4 Data collection

Part I and II: Internet discussion forum conversations considered to be part of the public domain were collected from the ten forums. While screening the forum posts, data was not collected if it stated that the person posting was under the age of 18. Only posts discussing issues related to heart failure were collected. Usernames were not extracted from the data, so all collected data remained anonymous; only the content of the post was collected. All other potentially identifying information was deleted to further protect the anonymity of the forum's participants. There was no participation in any of the online health forums and the health forums were publicly available and did not require registration/ membership to review the posts that were analysed. Socio-demographic data was collected but limited to what the online members wanted to share, for example: location, gender and age.

Part II: Responses posted between March 2016 and March 2019 were collected from each forum. This timeframe was chosen as the SIGN guidelines for heart failure were last updated in 2016. Data were not collected if it stated that the person was under the age of 18. The SIGN and NICE guidelines only apply to those over the age of 18 (NICE, 2018; SIGN, 2016).

4.5.5 Data analysis

Text posted between March 2016 and March 2019 was collected from each site for thematic analysis (Braun & Clarke, 2012). Once the data was collected, the forum posts were analysed. A thematic analysis was undertaken to establish a list of themes and sub-themes. A single post could represent multiple comments in different thematic categories. Most comments were anonymous and provided few details about the person, most commonly stating their age and gender. The appropriateness of the themes identified were verified by the supervisory team.

Part I: Themes were identified from the thematic analysis and then mapped onto the constructs of the NPT framework. During the process, common themes were identified and there was an indication of data saturation. Any data that fell outside the NPT framework was noted to ensure there was no “shoe-horning” of themes into the framework. The themes used in Chapter Six are presented descriptively alongside direct quotations from the forum posts and responses to show how the themes were justifiably derived from the data.

Part II: At the second stage of analysis, after thematic analysis and mapping themes onto the NPT framework, the quality of evidence of responses were analysed. The SIGN (SIGN, 2016) and the NICE (NICE, 2018) guidelines for heart failure symptoms and diagnosis were used as the gold standard with which to judge the quality of the information being provided to patients through the online health forums and compared the extracted content. The British Heart Foundation (BHF) (BHF, 2020) provides further lay information outside the scope of the guidelines and appeared most often in the search strategy; therefore, the BHF website was also used to compare the accuracy of responses, as people commonly used this source.

As the study was conducted within the UK and considering the types of responses and scale of the study, the NICE and SIGN guidelines were deemed most appropriate to be used after being carefully compared with the American Heart Association guidelines (AHA, 2017) to ensure similarity and appropriateness. If the content was not displayed within the guidelines, the BHF website (BHF, 2020) was looked at as ‘good evidence’, as this was a reliable and recognised information source that most frequently appeared in the search results.

The hierarchy of evidence based upon the John Hopkins nursing evidence-based practice guidelines (Dang & Dearholt, 2017), was adopted as a guidance to assess the levels and quality of evidence provided within the responses. The quality of evidence was categorised between levels one to five (see Table 4-3). High quality evidence included those aligned with the NICE and SIGN guidelines and good quality evidence included information within the BHF website. Level four included opinions of people signposting others to help inform decision-making. Level five was graded low quality evidence and split into three categories: lack of evidence, experiential or included potentially harmful responses that were inconsistent with the national guidelines or high quality and good evidence.

Table 4-3: Assessing the quality of evidence (based on the John Hopkins Nursing Evidence-Based Practice Guidelines)

Quality was assessed based on levels of criteria:

Level 1) High quality: Aligned with SIGN or NICE guidelines for heart failure – responses that contained information that can be found in the SIGN or NICE clinical guidelines for heart failure (does not have to include reference to guidelines).

Level 2) Good quality: Responses that included information that was supported by a mix of high- and moderate-quality evidence such as the BHF.

Level 3) Evidence based: Responses that included information that were not in the guidelines but were supported by some reliable sources but appeared inconclusive.

Level 4) Opinion: No advice given but opinion provided to help inform the next steps by signposting users to their HCP or other information sources.

Level 5a) Low quality/lack of evidence: Responses that offered advice based on an individual's personal experience but included no evidence.

Level 5b) Low quality/lack of evidence: Advice provided that was not deemed potentially dangerous but had no supporting evidence.

Level 5c) Non-evidence based and potentially harmful: Includes responses including information that is inconsistent with the national guidelines or high-quality/good evidence of best practice and may be harmful.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) was adhered to when reporting the results in Chapter Six (Appendix 10).

4.7 Phase three: a semi-structured interview study

4.7.1 Introduction

The fourth phase of the research reported in this thesis comprised an interview study aimed at generating a rich picture of the perceptions and interpretations of both public and HCPs regarding the phenomenon of interest – online health information seeking. In particular, it aims to address the following five research questions first presented in Chapter One:

RQ1. *How does online health information seeking affect the patient-HCP relationship and medical authority?*

RQ2. *How do HCPs perceive patients use of online health information and its effect on the patient-HCP relationship?*

RQ3. *How do public/patients perceive the use of online health information and its effect on the patient-HCP relationship?*

RQ4. *How does online health information seeking shape people's decision-making?*

RQ10. *What are the perceptions of online health information surrounding COVID-19 and the impact with information sources among healthcare services?*

The study is described using the COREQ framework for reporting qualitative studies (Appendix 11). This framework comprises three domains: research team and reflexivity, study design and analysis and findings together with a series of subdomains (Tong et al., 2007). It proposes a 32-item checklist for researchers to use to verify the thoroughness of their reporting. The domains and subdomains are shown in Figure 4-6. The prompts for researchers are aimed to ensure all items of the checklist are covered and have been used to complete this section. The checklist is appended as Appendix 11.

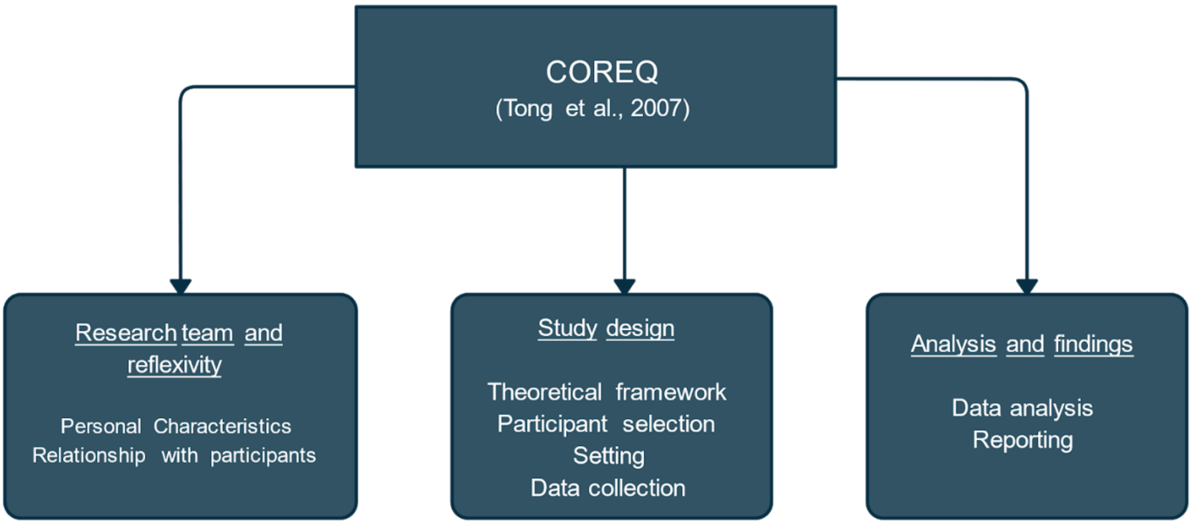


Figure 4-6: The COREQ framework for reporting qualitative studies

4.7.2. Research team and reflexivity

This research was undertaken by the author (full time PhD student in nursing at the University of Glasgow) with the guidance and support of a supervisory team comprising two supervisors. I conducted the interviews on a one-to-one basis and did so as part of my PhD programme. Prior to the operationalising of the interview study, I had some interviewing experience working as a research assistant however, as a nurse, one-to-one interactions with both patients and HCPs were not a new experience.

Reflexivity has general recognition as being a very important concept to qualitative researchers. It involves researchers developing an acute awareness of their own self while they construct the research situation. As reflexivity involves the acknowledgement that as a researcher, we are unable to totally avoid personal bias, some may interpret it as a weakness. In contrast, qualitative researchers such as Sweet (2020) situate reflexivity as a means to help researchers theorise the social world in relational ways. Reflexivity is present in the research process and can ultimately affect the research outcomes (Bradbury-Jones, 2007); hence, it is important for researchers to continually reflect upon their role in the research and how these effects may be influencing the research. It is important to address reflexivity and possible biases to resolve how problems may be avoided or minimised. This section will be written to reflect my own views and how they may have influenced the study.

4.7.2.1 Personal characteristics

Participants were made aware of my status as a PhD candidate as this was stated on the participant information sheet. However, it was also noted that while conducting interviews I was a researcher, therefore could not offer any medical advice or enter into conversations about the appropriateness of their care or treatment. There were no arising issues with participants. The participants were made aware the interviews were confidential which allowed them to be more open and honest about their experiences.

4.7.2.2 Relationship with participants

Platt (1981) highlighted a possible ethical issue that may occur when interviewing professionals within the same work setting which may affect the research process in terms of pressure and confidentiality. Therefore, it was important to ensure that a relationship of trust and ethical sensitivity existed both during and after the interview, and this was achieved throughout.

Participants had awareness of my knowledge of medical terminologies or understanding of their health experiences which allowed them to engage in deeper discussion. HCPs were able to discuss their perceptions using medical and professional terminology. However, while conducting the interviews, I addressed myself as only a researcher. This reduced the effect of any perceived power of the relationship that may have influenced the interview and its results.

My experience as a nurse helped guide my ability to empathise with public participants and HCP responses which is likely to have strengthened my interaction and resulted in higher quality data. This could have led to bias within the study however, I was clear throughout the study that my role was that of a researcher and it was essential to maintain neutrality.

Due to both geographic distance and limitations in place because of the pandemic, interactions prior to the interviews were impersonal, being conducted solely via email. Hence no relationship with participants was established prior to study commencement. The lack of detailed conversations prior to the interviews meant that aside from the status of the interview as a doctoral candidate and member of the nursing profession and other information provided on the participant information sheet, the participants had no indication of any biases, interests, or assumptions related to the researcher or the research.

4.7.3 Study design

Due to COVID-19, the study design needed modification to ensure safety with regards to the pandemic. The original plan was to conduct online interviews, focus groups and one-to-one semi-structured interviews. However, as face-to-face data collection was no longer considered safe, online interviews alone were used as the method of data collection.

Online semi-structured interviews were deemed a suitable data collection tool for this research as it focuses on digital health and recruitment irrespective of geographical location. Therefore, all participants were interviewed on Zoom (Zoom, 2016).

Interview discussions were conducted using a semi-structured interview guide. Transcripts were analysed in two stages: (1) thematic analysis (Braun & Clarke, 2012) to identify themes that were central to discussions; followed by (2) data analysis and conceptualising the data within the NPT theoretical framework. NVivo (QSR International, 2020) was used to help manage the qualitative data analysis process.

4.7.3.1 Theoretical framework

As explained in Chapter Three, the NPT framework was deployed as an explanatory framework and a thematic analysis (Braun and Clarke, 2012) approach was used for data analysis for this phase of the research. However, it was felt unnecessary to include mention of these tools in the briefing given to participants or to raise them during the interviews.

4.7.3.2 Participant selection

There were two populations for this study – HCPs and public participants.

HCP participants

This study aimed to explore the experiences of nurses, doctors and other HCP’s who may encounter patients using the internet for self-diagnosis. As the nursing profession continues to develop and grow and roles such as the advanced nurse practitioner and nurse specialist become more commonplace, it is important to understand nurses’ perceptions and behaviours towards internet-informed patients as they continue to transition into primary health provider roles. Historically, the doctor has always been the one to offer diagnoses. However, more nurses are accomplishing higher levels of training, becoming prescribers and have the ability to independently assess patients. It is important to have a firm understanding of nursing perceptions and their relationships with internet-informed patients as both the nursing profession and digital health era will continue to grow.

Similarly, doctors were a key population sample for this study. As mentioned above, doctors are historically known as providers of diagnoses and still play a key diagnostic role within the healthcare system. As the doctor's role has played a larger part with the diagnostic aspect of patient assessments, it is important to understand doctors' perceptions of the changes within their role from before internet health was a phenomenon, as well as an understanding of their perceptions of patients' growing use of the internet for health information.

Lastly, other HCPs such as physiotherapists were considered for this study. It is important to understand that other healthcare roles also play key roles in different aspects of healthcare diagnostics.

Public participants

As users of both online sources of health information and health systems themselves, the general public also experience first-hand the phenomena and relationships of interest in this research. As users of the health system, the terms public and patients are used interchangeably throughout this written report. However, to address the research questions it was necessary to have members of the public who have some familiarity with online health information seeking.

Potential study participants were evaluated using a screening process to assess their eligibility against the predetermined inclusion criteria. Participants who fit the criteria listed in Table 4-4 and Table 4-5 were eligible for inclusion.

Table 4-4: Healthcare professional eligibility criteria

Inclusion	Exclusion
• Healthcare professionals who have had experience working with internet-informed patients. • Any type of healthcare professional in any work setting. • Over the age of 18. • Able to speak the English language. • Any geographical location.	• Healthcare professional students. • Healthcare professionals looking up healthcare advice online. • Healthcare professionals using online health forums. • Under the age of 18. • Not able to speak the English language.

Table 4-5: Public eligibility criteria

Inclusion	Exclusion
• People who have experience using the internet for self-diagnosis and health information seeking. • People who have experience looking up health information on heart failure/heart conditions/heart symptoms. • People who diagnose their family/friend/relatives for heart failure/heart conditions/heart symptoms. • Over the age of 18. • Able to speak the English language. • Any geographical location.	• People who are not users of the internet for health information or have had no experiences. • People under the age of 18. • Not able to speak the English language.

Approaching potential participants online

Social media websites such as Twitter, Instagram, Facebook and other similar online spaces can offer platforms for connecting people with similar interests and sharing information, while allowing users to maintain physical separation and a degree of anonymity. A 2016 Pew survey found that 79% of internet users use Facebook; 24% use Twitter; and 32% use Instagram (Pew, 2016). Thus, recruitment through social media can reach larger and more diverse audiences. Social media sites have demonstrated a steady growth of academic interest across various domains such as health behaviours, mental health, medical research and other health-related topics (Fenner et al., 2012; Batterham, 2014; Ramo et al., 2010; Lohse & Wamboldt, 2013).

Recruitment was conducted through online platforms to recruit both public and HCP participants, and additionally through online health forums and the Alliance newsletter (Health and Social Care Alliance Scotland, 2021), to recruit further public participants (Appendix 12-13). Snowball sampling (Sharma, 2017) was encouraged by requesting participants share the posts made on these platforms or pass the information to people they thought may be interested and met the eligibility criteria.

Twitter

While Facebook is globally the most popular social networking site, Twitter is the most popular microblogging platform with nearly 650 million actively monthly users as of April 2019 (Statista, 2019). Twitter is an efficient and valuable platform for recruiting participants for research studies as it can reach a diverse, disparate and wide audience (Sinnenberg et al., 2017). Twitter has received growing interest within the research community for its potential as a tool for gathering public opinions and social movements (Tumasjan et al., 2010).

Hashtags are a social media function to help reach wider audiences. Using hashtags such as ‘#heartfailure’, allowed the recruitment post to become visible on users’ home pages who are interested in the topic area. Twitter allows for monitoring of each post you make. For example, once a tweet is published, you are able to see statistics of how many people the tweet reaches. This allows for reflection on any alterations that could be made to the next post if the reach has not gone as far as hoped.

Four rounds of recruitment were published on Twitter. The first recruitment tweet had a total of 7060 impressions and 352 engagements; second - 3154 impressions and 124 engagements; third – 6736 impressions and 451 engagements; and the fourth – 3901 impressions and 204 engagements. Impressions and engagements can be heavily influenced by the time of day the tweet is published.

Any users who responded to the tweet publicly, were asked to have further contact through email so that any further discussions related to the research project were confidential.

Overall, Twitter was a powerful recruitment tool as it allowed the process to target people within a particular area of interest; and it provided a personal approach to recruitment as it allowed person-to-person engagement, with users able to see the researcher's profile. Six out of thirty-one participants were recruited from Twitter.

Instagram

Instagram works well for recruiting those of the younger generation (Thomas et al., 2020). Previous studies had shown success in recruiting through Instagram (Chu & Snider, 2013; Batterham, 2014; Berg et al., 2015). Instagram is among the most frequently used tools by the World Health Organisation and other public health agencies for disseminating health-related messages (Kamel et al., 2016; Guidry et al., 2017). It shares many of the same functions as Twitter in different formats. On Instagram, users can comment on posts that are published and can also share them to their story. Instagram stories allow users to share posts with a 24-hour time period, after which they expire. Similarly, to Twitter, Instagram also has monitoring functions where one can evaluate post statistics such as reach. Three rounds of recruitment were posted on Instagram. The first post had a total of 2463 impressions; second – 1817 impressions; and the third had 1833 impressions. For this study, eleven out of thirty-one participants were recruited from Instagram.

Facebook

Facebook is the most popular social networking forum with roughly 2.8 billion monthly active users worldwide (Statista, 2020). Facebook's ability to reach populations across geographical locations and user demographics is a strength within its recruitment appeal (Burbary, 2011). A previous literature review highlighted one of the benefits of using Facebook in research recruitment are its ease of use and cost-effectiveness (Park & Calamaro, 2013).

Facebook represents a potentially fast and affordable method of recruiting study participants for interview research. It also allows for snowball sampling as Facebook friends can further share with their own contacts. Facebook does not have monitoring functions like Twitter and Instagram; therefore, these statistics were not available for evaluation within this recruitment process. Two rounds of recruitment were posted on Facebook and five out of thirty-one participants were recruited from Facebook.

Online health forums

Online health forums were another tool employed to recruit participants for the interview study. The qualitative study of online health forums completed prior to this, had ethical approval and online health forums that met the eligibility criteria were used for consideration for this study.

Using online health forums enabled the research to reach users who are actively using the internet for health information, and this was thought to be a useful recruitment source of people experiencing heart symptoms. Some forums have sections dedicated to research studies seeking participants. However, this recruitment source was not as useful as expected. Perhaps because the users of these forums felt more purpose in the ‘peer to peer’ element of the forums and not research recruitment. Some of the larger forums had policies that denied permission to post about research studies. Other studies have had similar experiences (Morgan et al, 2013), while some had success (Ip, 2010).

Terms and conditions of the selected public health forums were thoroughly read. If terms of the forums explicitly stated that research posts were not allowed to be posted, this was automatically excluded. If terms did not state any issues with regards to research posts, website administrators were contacted to ensure this was allowed before posting.

Five online health forums were excluded as the terms and conditions explicitly stated not to post research. The researcher contacted the remaining five online health forums’ website administrators for permission to post. Three allowed the posting and two declined. The two forums that declined provided reasons such as the safety of the users on the forums; to allow the forum to be used as a peer communicative platform instead of being approached by research studies; and that their user feedback drew them to the conclusion that they should no longer allow links to surveys or research recruitment within their forums. Two people responded to the recruitment post on two separate online health forums. One did not go ahead with the interview due to a period of ill health.

Alliance recruitment

The Health and Social Care Alliance Scotland (ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. Alliance published the recruitment flyer for this study in their newsletter. The newsletter was successful, and three people responded to the flyer. One person did not respond after initial contact and the two remaining respondents were consented and recruited as participants within the study.

No participants asked to be removed from the study once they had taken part in the interview and no interviews had to be repeated.

Table 4-6 summarises the results from each of the recruitment platforms and also shows the number of dropouts and reasons.

Table 4-6: Total number of respondents and participants

Recruitment platforms	**No. of respondents**	**No. of final participants**	**Reasons provided for respondents not participating**
Twitter	7	6	Did not meet eligibility
Instagram	11	11	Did not respond
Facebook	6	5	Did not respond
Online health forums	2	1	Dropped out due to ill health
Alliance	3	2	Did not respond
Snowballing	6	6	N/A
Total	**35**	**31**	

After reacting positively to the recruitment efforts, participants made initial contact by email. After this, participants were sent a participant information sheet (Appendix 14); consent form and privacy notice (Appendix 15-16) which outlined further details of the study. Participants who were still keen to take part in the study, signed and returned the consent form and a date and time for the interview was agreed. As this study was international, I took account of the time differences and made sure it was a straightforward process for the participants regardless of these differences in time.

Each participant who expressed interest in the study was contacted via email, to establish that they were happy to be interviewed. Participants were given the opportunity to ask any questions they had about the study and what would happen if they agreed to be interviewed. Each participant was asked if they had had the opportunity to read the information sheets to ensure they had read and understood them.

To recap, a total of sixteen public participants and fifteen HCPs participated in a one-off online interview. Informed consent and basic demographic information were collected from each participant. Each interview lasted approximately 40-60 minutes. Data collection for this study took place from August 2020- January 2021.

4.7.3.3 Setting

This was an online semi-structured interview study, wherein all interviews with participants took place on Zoom (Zoom, 2016). Participants were also offered Skype or an audio phone call in case they had preferences for these alternatives. However, although it was offered, no preferences from any interviews were suggested as to means of contact, therefore all interviews were held on Zoom. In this sense you could call the setting a virtual one. The interviews were one-to-one with nobody else present. The characteristics of the two subsamples including demographic data are reported in Chapter Seven which presents the findings of the study.

4.7.3.4 Data collection

Data were collected through semi-structured interviews to facilitate open discussions which were guided by the interview schedule discussed below and presented in Appendix 17-18.

The interview schedule was developed to probe deeper into questions which served to explore the aims of the research. The interview schedule was constructed on the basis of the studies completed prior to this. The key areas developed were the overall perceptions of HCPs and public participants for people’s use of the internet for health information.

To design the tool that would be used in each of the interviews, I followed a six-stage process as outlined by Braun and Clarke (2013): brainstorming initial questions, considering the sequencing of questions, constructing and wording the questions, developing prompts and probes, piloting the interview guide and finally refining the interview guide.

Brainstorming initial questions

Initial questions were informed by my previous work of understanding peoples use of the internet for health information and online health forums; evaluating the perceptions of the public and HCP's; and understanding the impact internet health information has on the patient-HCP relationship.

Sequencing of questions

I began a process of grouping questions by 'topic' or 'theme' in order to sequence the questions. I decided that the most logical way to sequence them was through the stages of the decision-making process journey concluded in one of the previous studies in this PhD: gaining an understanding of their experiences, understanding what they know surrounding the topic; how they use the internet; peer to peer healthcare; making contact with the HCP's or addressing the consultation process; information needs; relationship between patients and HCP's; and overall perceptions of uses of the internet for health information and overall impact of its use on the patient-HCP relationship.

Constructing and wording the questions

The next stage was considering how the questions may be worded. It was important to consider the two different sample groups – public and HCPs. However, I kept the wording similar for both groups. In order to allow the interview to progress in a conversational manner, strict questions that had to be adhered to were not developed. Instead, example phrasings were developed whilst being mindful that the wording of the questions may change depending on how the participants responded to previous questions. I wanted to allow the conversations within the interview to emerge in a natural but purposeful way (Burgess, 2002), while being mindful of the specific topic areas I wanted to address.

Developing prompts and probes

The next stage of the process was to develop a set of prompts and probes for my questions. Prompts and probes can encourage participants to open up and expand upon their answers in further detail. Prompts and probes were developed for each question.

Piloting and refining the interview guide

The final stages of the development of the interview schedule were to include the piloting of the tool and refining it before employing it with participants. The tool was appraised and agreed with the supervisory team. Prior to the interviews, I completed online communication courses and I undertook several 'mock interviews' with colleagues to ensure I was happy with the wording of the questions, the flow of the interview and to check the equipment was working efficiently prior to embarking on the participant interviews. I subsequently conducted the online interviews independently.

Interview schedules were also constructed in such a way that would elicit information about the process of normalisation through "making sense" of people's use of the internet for health information (coherence); "working out participation" through peer-to-peer healthcare (cognitive participation); "doing the work", what they do with the collected health information (collection action); and "acting on it" their relationships with their HCP's (reflexive monitoring). The interview schedules are appended as Appendix 17-18.

4.7.4 Analysis and findings

4.7.4.1 Data analysis

After each interview, key points arising were summarised and notes were made on participants' tone and language. Each participant's interview was individually analysed. Each transcript was read whilst simultaneously listening to the tape. I transcribed twelve of the audio-recordings independently and had these spot checked by one member of the supervisory team. This allowed me to become familiar with the data before the formal analysis process. The remaining transcripts were sent to a professional transcription company.

During this process of familiarisation, descriptive notes were made about language used, inconsistencies in the participants responses, repeated phrases, and questions about the data. In line with the earlier comments on reflexivity, a research diary was maintained to detail personal emotions and preconceptions that may affect analysis, in an attempt to acknowledge and lay aside personal opinions as a form of bracketing (Smith et al., 2009; Creswell, 2013).

Each transcript and accompanying notes were then re-read. NVivo was used to manage the data and facilitate the organisation of data into themes. At this stage I was not only abstracting themes but also looking for connections between the themes in each transcript.

Data analysis was guided by Braun and Clarke's (2012) six stage thematic analysis framework. All transcripts were coded and agreed by the research team. Care was taken in the reporting stages to ensure they were a true reflection of participants' experiences, with NPT used as a confirmatory tool to abstract the descriptive themes from the analysis to implications that were relevant and grounded in the findings.

The next stage of analysis consisted of taking these newly developed themes and arranging them into a logical structure of concepts. This stage of analysis aimed to group themes into predominant categories and identify relationships between them.

Once the inductive coding was complete, themes were then mapped to ensure they were distinct from one another and to show how the themes fit together. At this point, the constructs of NPT were cross referenced against the derived themes to see if NPT could illuminate the themes derived from the data. This stage was performed to ensure that themes were directly derived from the data and the data was not forced to fit the constructs of NPT. NPT was used as a theoretical lens with which to interrogate the findings.

Four constructs: “making sense of it” (coherence), “doing it”, (collective action), working out participation (cognitive participation), and “reflecting on it” (reflexive monitoring) were all helpful when making sense of the data. NPT allowed the emergence of implications for policy, practice and further research (discussed in Chapter Nine). The themes were then given names and made ready for reporting.

All interviews were conducted, and transcripts were coded by myself. A supervisory meeting was held to discuss the patterns and themes evident in the transcripts to ensure consistency of coding and to ensure that any themes were not being overstated.

4.7.4.2 Reporting the findings

The findings of this phase of the research are presented in Chapter Seven. The chapter is divided into two main parts where firstly the findings from the public interviews are given, and secondly those from the HCP interviews. The findings are presented descriptively alongside data fragments in the form of direct quotations from the interview transcripts to justify how the themes were derived from the data and to provide a narrative style exposition of the responses given to the researcher's questions. Where a data fragment was used, the participant was identified by means of a numeric, and so anonymous, identifier.

4.8 Ethical considerations

4.8.1 Ethics applications

The University of Glasgow requires that all research involving human data is subject to formal ethical review and approval. Research committees need to be provided with evidence that ensures the subjects involved in, or affected by the study will not be harmed, and that all participants will receive fair and ethical treatment. I attended appropriate training such as the NHS Research Good Clinical Practice Training as well as courses within the University of Glasgow such as ethical approval for people working with human subjects and research integrity training.

The research proposals to collect data from online health forums (200180115) and to conduct interviews (200190100) were submitted to, and approved by, the College of Medicine, Veterinary and Life Sciences ethics committee at the University of Glasgow in April 2019 for the online health forum studies, and July 2020 for the interview study (see Appendix 19-21). Ethics applications were prepared to submit to the University of Glasgow and NHS ethics committee. However, due to the COVID-19 outbreak and data collection being halted within the university, the NHS ethics committee closed and paused research applications and were only considering COVID-19 studies (NHS Research Scotland, 2020). Therefore, it did not seem sensible to attempt to submit an application to the NHS and was also not safe to conduct face-to-face interviews, focus groups and recruit patients through NHS services. Therefore, ethical approval was only submitted to the University of Glasgow.

The University of Glasgow stopped all data collection with the exception of COVID-19 studies, in the initial period of the COVID-19 outbreak. This delayed the interview study from beginning as planned. The research ethics committee of the university informed all researchers and supervisors that data collection could not go ahead and would be postponed until further notice (University of Glasgow, 2020).

An amendment was submitted for the interview study to include recruitment of all HCP’s as opposed to those who have only had experiences with patients who self-diagnose heart failure, as it became apparent that many HCP’s may not have had specific experiences with only heart failure/conditions but may still have perceptions about the topic itself (see Appendix 22). The two online health forum studies were included within the one ethics application as the same data set was used to inform both studies.

All applications submitted to the ethics committee for approval were written independently by myself, with support and advice from my academic supervisors to review and validate the required information before submission and aims were discussed with PPI members.

4.8.2 Informed consent

4.8.2.1 Online health forums

Informed consent was not sought as the data was collected from open access websites already in the public domain. It did not involve any direct communication with study participants. Forum names were removed from the data to ensure anonymity of the members.

4.8.1.2 Interview study

Written and verbal informed consent and basic demographic information were collected from each participant. Prior to the interview, each participant received a consent form, privacy notice and a participant information sheet (Appendix 14-16). Participant interviews were audiotaped with consent. Participant demographics such as age, gender, employment status and location were collected. Only participants over the age of 18 were included.

Online interview consent was obtained by emailing all necessary documents to participants using my university email. People willing to participate were asked to return the signed consent forms to the same address. The respondent had the option to print out the consent form to sign and send it back or provide an electronic signature. If they were unable to do either of those options, they were asked to type their name into the signature box and email it back from their email address. Additionally, at the beginning of the online interview, they were also asked to confirm their consent and signature on the form.

Participants were informed they had the right to withdraw from the study at any point, which was also clearly stated on the consent forms. If they chose to withdraw, their data would have been removed from any transcripts, analysis or the write up of this study. Participants were also reassured that non-participation or withdrawal from the study at any stage, without explanation, would not incur any negative consequences.

4.8.3 Data Protection Impact Assessment

A Data Protection Impact Assessment was submitted to the University of Glasgow data protection office for the semi-structured interview study which was granted approval on the 21st January 2020 (see Appendix 23). This is a process for building and demonstrating compliance and trust. It ensures that strict and confidential data processing is implemented into the research project.

The General Data Protection Regulation course and information security course through University of Glasgow guidelines were followed. I attended appropriate training of research data management courses within the university which included data handling, good research data practice and data management.

All data within this study was kept strictly confidential and all data was pseudo anonymised. The data was transferred directly to the university shared drive where only my two academic supervisors and I have access. This data was password protected and only accessed through my university account. In alignment with the University of Glasgow guidance on managing research records, the data will be kept for ten years.

Each phase of this research was low-risk, and the main ethical consideration was to ensure that confidentiality was in place and to make sure there was no disclosure of any identifying information of participants. No identifiable information was used that can breach any confidentiality. All personal information was kept strictly confidential. Participants were made aware they have the right to withdraw at any point during this study and it is their choice if they would like to participate or not. However, the data collected from participants until that point, could be kept with full confidentiality. As a registered nurse, I acknowledge the importance of confidentiality and adhere to the Nursing and Midwifery code of conduct (NMC, 2015). Storage limitation access restrictions were implemented by storing the data where it was only able to be accessed by myself during the data collection and analysis process.

Participation was on an entirely voluntary basis. Participants had no means of access to the data; however, each participant was asked if they would like to be kept up to date with the findings of the study.

As the University of Glasgow is the data controller, they have the right to ensure the security of the identifiable data. In the case of evaluation or audit by regulatory authorities, it was upon agreement to keep records, identity of participants, original signed informed consent, recorded and verbatim data, confidential and anonymous.

4.8.4 Collecting data during a pandemic

The coronavirus pandemic which began to seriously affect the UK from March 2020, brought with it additional ethical considerations. Researchers in some fields faced the challenge of hard-to-reach groups, particularly when conducting interview studies. For health researchers, these groups are often those who do not engage with health services and perhaps those for whom English is not their first language (Rockliffe et al., 2018). However, there are rare instances when the entire population becomes hard to reach. The COVID-19 pandemic of 2020 saw both academic institutions and the wider society, subject to a broad range of restrictions on social interactions. For example, a two-metre social distance rule was introduced by the Scottish Government on 23rd of March 2020. Ethical considerations and in particular, the requirement for the avoidance of harm to participants and/or the researcher also ruled out in-person data collection, leaving the choice of fieldwork deferment or online data collection. Deferment of the fieldwork for the present study was considered but rejected for two reasons. Firstly, there was a strong possibility that the interruption to normal fieldwork would be a lengthy one. The Social Science Research Council was among the organisations expressing a cautious view as to when in-person fieldwork would recommence, with one article assessing that “most field research… is unlikely to resume safely in 2020 and may not be logistically and ethically feasible in many settings until at least summer 2021” (SSRC, 2020). The same article highlighted the responses of researchers, including a move to online data collection. In the U.S., the American Psychological Association also contributed to the debate on field research during the pandemic pointing out that “many … researchers who rely on face-to-face interaction to collect data — will have to hit pause or go online.” (APA, 2020). Based on advice from the NHS and the University of Glasgow research ethics committee, all research, which included face-to-face contact was suspended from March 2020.

Hence, the general message coming from authoritative bodies was that any deferment of fieldwork would likely not be a short term one and that for many researchers, online data collection should be considered. The second reason for continuing with the planned fieldwork timeline was that the new strategy of collecting data from online interviews was sufficiently robust and supported by the literature (Archibald et al., 2019; Irani, 2019; Lobe et al., 2020; Gray et al., 2020) and I judged that the quality of the study could be maintained while at the same time maintaining the planned schedule.

4.9 Chapter summary

This chapter described and discussed the methods used to conduct each phase of the research reported in this thesis. It also explained how triangulation was applied to a sequential design so that the research problem and the research questions set in the first chapter could be thoroughly addressed. The chapter closed with consideration of the ethical dimensions of the research and the particular issues raised by conducting research during a pandemic. With the methods now set out, the following three chapters present the findings of the three phases of the research starting with the systematic review.

Chapter 5 - Findings: Mixed Methods Systematic Review

5.1 Introduction

This chapter presents the findings of a mixed-method systematic review of quantitative, qualitative and mixed method studies concerning the public and HCP's perceptions of online self-diagnosis and health information seeking and how this can impact the patient-HCP relationship. In this sequential research, this review represented phase one of the work.

Previous research on the topic of online self-diagnosis and health information seeking tends to focus on the quality of health information online (Benigeri & Pluye, 2003) and the characteristics of online health information seekers (Koch-Weser et al., 2010). Other research has explored patient satisfaction with HCP communication and patient-HCP interaction (Hou & Shim, 2010). This systematic review investigates whether patient online self-diagnosis and health information seeking is affecting the patient-HCP relationship, and the perceptions of patients and HCPs regarding online self-diagnosis and searching for health information online. The patient-HCP relationship has been known to influence health outcomes and can improve the patient experience in the healthcare system (Sabater-Galindo et al., 2016; Fox & Chesla, 2008), hence efforts to understand whether and how this relationship may be influenced by increased health information seeking online is an important evidence gap.

This paper aims to address the following three research questions first set out in Chapter One:

RQ1. *What are the effects of patients seeking online health information on the healthcare professional-patient relationship and medical authority?*

RQ2. *How do healthcare professionals perceive patients' use of online health information?*

RQ3. *How do public/patients perceive the use of online health information?*

The methods used in this systematic review were detailed and discussed in Chapter Four and the search protocol was registered on PROSPERO (Appendix 3). After presenting the core constructs of the NPT coding framework and the themes and subthemes which emerged from the data as a result of the coding process, the rest of the chapter is organised in accordance with these themes/subthemes.

5.2 Study characteristics

After the updated literature search described in Chapter Four, there were a total number of 32 eligible papers, including 18 qualitative, 13 quantitative and 1 mixed method study (see Appendix 5-7). Five studies had taken place in the United Kingdom (Bowes et al., 2012; Ahluwalia et al, 2010; Bartlett & Coulson, 2011; Donnelly et al., 2008; Stevenson et al., 2007), six from the United States (Imes et al., 2008; Rupert et al., 2014; Macias & McMillan, 2008; Bell et al., 2011; Hay et al., 2008; Fiksdal et al., 2014), five from Israel (Russ et al., 2011; Barnoy et al., 2011; Giveon et al., 2009; Barnoy et al., 2008; Ohana & Barnoy, 2019), four from Canada (Townsend et al., 2015; Silver, 2015; El Sherif et al., 2018; Audrain-Pontevia & Menvielle, 2018), three from Switzerland (Sommerhalder et al., 2009; Caiata-Zufferey & Schulz, 2012; Caiata-Zufferey et al., 2010), three from China (Chu et al., 2017; Lu et al., 2018; Zhang et al., 2021), two from Australia (Benetoli et al., 2018; Lee et al., 2014), one from Austria (Haluza et al., 2017), one from Portugal (Mendes et al., 2017), one from Belgium (Huisman et al., 2020), and one from India (Singh & Banerjee, 2019).

The sample sizes ranged from 11 to 975 with participants including patients either posting online or attending clinical settings, carers, and HCPs ranging from physicians such as GPs, nurses and various other HCPs. Participants were from a variety of ages, genders, socio-economic groups and ethnicities. Although, studies more frequently included middle-aged females and those of ‘white’ ethnicity. Full details of study characteristics are provided in the data extraction tables in Appendix 5-7 and further details of participant characteristics are provided in Appendix 8. Five studies explored only the HCPs perspectives compared to the patient’s perspectives.

5.3 Quality assessment of included studies

The quality of reporting in the included studies varied and was measured using the mixed methods appraisal tool (Pluye et al, 2009). All 32 studies presented clear research questions and collected data to address the questions. Most of the qualitative studies used appropriate data collection methods to answer the research questions. The findings were reported adequately, derived from the data and provided coherence between qualitative data sources, collection, analysis and interpretation. Most quantitative studies used appropriate statistical analysis to answer the research questions and used appropriate measurements. Almost all the quantitative studies had pre-tested and piloted surveys before use. Fewer studies had samples that accurately represented the target population. Overall, the studies were of moderate quality. See Appendix 9 for the full quality assessment mixed methods appraisal tool (Pluye et al, 2009).

5.4 Data analysis/synthesis

All papers were thematically analysed and mapped onto the constructs of the NPT framework (Table 5-1). The NPT coding frame is based on the publication of this systematic review (Farnood et al., 2020).

Table 5-1: Normalization Process Theory coding frame. Based on Farnood et al. (2020)

Coherence (Sense-Making Work)	**Cognitive Participation (Relationship Work)**	**Collective Action (Enacting Work)**	**Reflexive Monitoring (Appraisal Work)**
Differentiation	**Initiation**	**Interactional workability**	**Systemization**
Understanding the differences between peoples' use of the internet for online self-diagnosis with the healthcare professional's diagnosis.	HCPs communicating and recommending online health websites to people.	Bringing online health information to consultations and the effect on the consultation and communication between the patient and HCP.	Determining the benefits and risks of online self-diagnosis.
Communal specification	**Enrolment**	**Relational integration**	**Communal appraisal**
Using online health forums and communities to gain information and self-diagnose.	HCPs reactions and behaviours towards internet-informed patients.	The influence (e.g., on confidence) of bringing online information to the relationship between the HCP and internet-informed patients.	Sharing online health information with HCPs and how HCPs react to this.
Individual specification	**Legitimation**	**Skillset workability**	**Individual appraisal**
People achieving an understanding of health information gained through the internet.	HCPs perspectives of online self-diagnosis and if they believe this is beneficial or the right thing for people to do.	The effect of using online information on roles and responsibilities of members of the public or HCPs.	Judging the quality of online information; to what extent do the public or HCPs think the information on the internet is reliable and accurate?
Internalization	**Activation**	**Contextual integration**	**Reconfiguration**

Peoples understanding and perceptions of using the internet to self-diagnose and knowing if this is their preference or if they value the role of the HCP consultations instead.	Communicating effectively with internet-informed people and adapting behaviour towards them.	Integrating online self-diagnosis into social circumstances.	Understanding how online self-diagnosis affects the patient-HCP relationship and altering behaviour and reactions to ensure it is a positive change.

Four major themes and several subthemes were identified from the synthesis of the literature. The four main themes are: 1) patient perspectives on using the internet to seek health information; 2) healthcare professionals' perspectives on and reactions to internet-informed patients; 3) sharing online health information with healthcare professionals; 4) impact of online medical searches and diagnosis on patient-healthcare professional relationships (Table 5-2).

Table 5-2: Themes and sub-themes

Theme 1: Patient perspectives on using the internet to seek health information	
Subtheme 1: Reasons for using the internet	Why patients/public use the internet for healthcare advice.
Subtheme 2: Reasons against using the internet	Why patients/public are against using the internet for healthcare advice.
Subtheme 3: The prepared patient	Why patients/public felt the importance of being prepared for consultations and more informed of their health.
Theme 2: Healthcare professionals' perspectives on and reactions to internet-informed patients	
Subtheme 1: HCP's perceptions for and against people using the internet for online health information	HCP's reasons for and against patient/public use of the internet for health information.
Subtheme 2: HCP's reactions and behaviours to internet-informed patients	The importance of reactions and behaviours from HCP's when faced with internet-informed patients.
Theme 3: Sharing online health information with healthcare professionals	
Subtheme 1: Communication	Enabling better communication within the consultation.

Subtheme 2: Bringing online health information to the consultation	The decision of whether patients/public would disclose or not disclose their online health information research to their HCP's.
Theme 4: Impact of online medical searches and diagnosis on patient-healthcare professional relationships	
Subtheme 1: Trust	Patient/public's trust in the internet and HCP's.
Subtheme 2: Role changing	Change in the HCP-patient roles.
Subtheme 3: The patient-HCP relationship	How has online self-diagnosis affecting the patient-HCP relationship.

Participant quotes are provided in the text to corroborate the data in each theme and are summarised in Table 5-3.

Table 5-3: Participant quotes supporting themes

Themes	**Participant quotes**
People's perspectives of online self-diagnosis and online health information seeking **Coherence (CO)**	**Reasons for using the internet** • "I use the Internet at home and in the office, and it is very easy, easy and most of all rapid. You lose very little time. . . And when you find what you need, then you can come back later and in a little moment I can see all the new things. So, why should I not use it?" (Caiata-Zufferey et al, 2010) **Reasons against using the internet** • "There is so much information. For example, if I wanted information on healthy diet and how to lose weight, when you search, heaps and heaps of information comes up. So it's really difficult to decide which to use, let alone whether it's actually suitable for me or not, or even whether it's trustworthy." (Chu et al, 2017). **The prepared patient** • "…to go in feeling like you at least know maybe what to expect…and you know what questions to ask. Because sometimes going to the doctor is intimidating and then they…use the medical talk and you're like, 'I don't really know what that means,' so at least if you've read a little bit,

	you feel more prepared and can say, 'Well, what about this?"' (Rupert et al, 2014).
Healthcare professionals' perspectives of people online self-diagnosis and online health information seeking **Cognitive Participation (CP)**	**HCP's perceptions for and against people using the internet for online health information** • "I think it is a good thing for patients to have access to medical information. … But this only applies to high-quality information. Because it makes people proactive. For instance, it makes people aware of insidious health problems that are often discovered too late." (Caiata-Zufferey & Schulz, 2012). • "For me that was the irritation, that the patient had far more trust in the computer and what they found on the web than in what I was trying to explain.' (Ahluwalia et al, 2010). **HCP's reactions and behaviours to internet-informed patients** • "I've…decided that right upfront if somebody has clearly done way more reading into an area that I'd ever done I just say: 'Wow, you know more about that than I do'…It's really important not to feel threatened by that information because…if you [did]…that will affect your relationship" (Townsend et al, 2015).
Sharing online health information with healthcare professionals **Cognitive Participation & Collective Action (CP & CA)**	**Communication** • "a huge difference…finding information, and what it means, before you go to the doctor so you can have an intelligent conversation…[and] ask them the right questions" (Townsend et al, 2015). **Bringing online health information to the consultation** • "I kind of watch the way you say it because you don't want to offend [doctors]. I would just kind of say 'I didn't know whether it could be this'…and introduce it like that." (Rupert et al, 2014). • "I think they [HCPs] probably take you a bit more seriously when you know your stuff, because they can't fool you around, because they know that you have the answers" (Benetoli et al, 2018).
Impact of peoples use of the internet for self-diagnosis and health information seeking on their relationship with healthcare professionals **Reflexive Monitoring (RM)**	**Trust** • I wouldn't trust a computer that much ... any specific information like 'do this' or 'don't do that', because – even though it may be useful, I'd much rather deal with a human being, a doctor (Stevenson et al, 2007). • "If you spend that last five minutes…showing them [patients]…"This is a website that you can read too. It's got enough information but not too much and it won't overwhelm you. This is endorsed by the Canadian Arthritis Society." It kind of builds a level of trust and…adds a component of enrichment to the appointment… they read

	about it and I think they just feel a lot more like, empowered and cared for … equipped." (Townsend et al, 2015). **Role changing** - "That's what I've been experiencing by now for the last 20 years; my professional authority isn't as sacred as it used to be. I can't say anymore that's it, that's what I see, this is what we know and the patients are trusting and believe that we know best. It's no longer like this." (Sommerhalder et al, 2009). **The patient-HCP relationship** - "It's just helped me have…more of a conversation with my doctor rather than just being, you know, have a one-sided, just listening. I feel like I can be more active in that interaction." (Rupert et al, 2014) - "You just have to be really open to the fact that they're [patients] going to tell you things you didn't know and that's great. "Oh I hadn't seen that before. That might be useful for me with other clients". So I definitely feel it's more of a partnership…". (Townsend et al, 2015).

5.5 Patient perspectives on using the internet to seek health information

People's opinions of using the internet for self-diagnosis differ, with diverse views expressed across the studies. Fourteen qualitative studies (Donnelly et al., 2008; Stevenson et al., 2007; Macias & McMillan, 2008; Fiksdal et al., 2014; Townsend et al., 2015; Silver, 2015; Benetoli et al., 2018; Lee et al., 2014; Sommerhalder et al., 2009; Caiata-Zufferey et al., 2010; Mendes et al., 2017; Chu et al., 2017; El Sherif et al., 2018; Huisman et al., 2020), one quantitative (Audrain-Pontevia & Menvielle, 2018) and one mixed methods study (Hay et al., 2008), reported on this theme. Essentially, there were three sub-themes relating to: 1) why people used the internet to seek health information; 2) concerns about using the internet; 3) and a desire to be a "well informed" patient. These relate mostly to the NPT theoretical constructs of coherence (sense making) and reflexive monitoring (appraisal). However, some of the issues raised related to collective action (enacting work) when considering the effort involved in searching for information online.

Essentially, the internet was thought to be informative, but there was evidence that people had concerns about the quality of the information available, with the belief it could be contradictory at times and should be seen as provisional (Townsend et al., 2015). Contradictory information could result in additional questions arising about health and trigger a seemingly endless cycle of information seeking (Townsend et al., 2015; Silver, 2015).

5.5.1 Reasons for using the internet

Patients viewed the internet as useful for finding out more information about their health conditions or the medications prescribed by their HCP (Lee et al., 2014; Huisman et al., 2020). Self-diagnosing symptoms while remaining anonymous such as by posting in online health forums was popular (Fiksdal et al., 2014; Mendes et al., 2017; Audrain-Pontevia & Menvielle, 2018) for a number of reasons. For example, people in countries where patients pay for their healthcare reported online self-diagnosis to be money saving and time efficient. They could access health information with ease for free as opposed to waiting for a healthcare appointment and then having to pay a fee (Fiksdal et al., 2014).

Patients reported that the internet was often the first source they accessed for health information. Patients found the internet convenient and allowed them to become more self-aware and to share their experiences within online health forums (El Sherif et al., 2018; Audrain-Pontevia & Menvielle, 2018). It allowed patients and the public to expand their knowledge and gain a deeper understanding of health information without involving their HCP. It was also seen as beneficial to be able to revisit the information as many times as required for free (Rupert et al., 2014; El Sherif et al., 2018). The internet was generally seen as a tool for seeking information on the treatment of non-serious medical issues or for self-diagnosis (Haluza et al., 2017).

Accessibility and speed were key identified benefits of online self-diagnosing (Huisman et al., 2020). The internet allows 24-hour access, whereas obtaining an appointment with a HCP can be difficult (Donnelly et al., 2008; Stevenson et al., 2007; Macias & McMillan, 2014; Huisman et al., 2020).

> The Internet is really easy to use, you can use it anytime. Unlike doctors or health clinics, I can’t call them and ask them at work, and after work, they are all closed. But with the Internet, you can search the information during work, and even after work, you can use your mobile phone to go on

> the Internet to search. I think this is really convenient and because it's the Internet, it offers you more sources and opinions (Chu et al., 2017, p.5).

5.5.2 Reasons against using the internet

There were reported concerns about the credibility, limitations and trustworthiness of online information (Silver, 2015; Chu et al., 2017). Difficulties included information overload and complex or contradictory information (Sommerhalder et al., 2009; El Sherif et al., 2018). Searching for health information online demands time, energy, and physical effort, especially for those not as familiar with technology (Townsend et al., 2015; Silver, 2015; Chu et al., 2017). One qualitative study reported that a significant minority of patients (31%) believed that advice taken from the internet was not personalised to their clinical situation or based on their past medical history, preventing accurate self-diagnosis (Chu et al., 2017). The overwhelming amount of information online can also result in the masking of credible sources (Mendes et al., 2017). This impacts patients' ability to depend on information and causes the public to find the internet less reliable than other sources of information such as HCPs (Mendes et al., 2017). However, most patients viewed their online research as a complementary information source to be used alongside treatment and advice from their HCP (Donnelly et al., 2008; Hay et al., 2008; Sommerhalder et al., 2009; Caiata-Zufferey et al., 2010; Mendes et al., 2017). HCPs were thus viewed as expert guides who could aid navigation through the otherwise overwhelming quantities of online health-related information (Townsend et al., 2015). The internet was seen to work well as a means for self-diagnosis or to find information to help ease patients' minds while awaiting doctors' appointments (Donnelly et al., 2008).

> I wouldn't trust a computer that much ... any specific information like 'do this' or 'don't do that', because – even though it may be useful, I'd much rather deal with a human being, a doctor. (Stevenson et al., 2007, p.6).

5.5.3 The prepared patient

Some people saw online self-diagnosis as a method to increase their knowledge, making them better prepared and equipped for health consultations (Audrain-Pontevia & Menvielle, 2018). Having a better understanding of symptoms and conditions was thought to help them to engage more effectively with HCPs. It was also seen as a way to help them make the most of the short time they have in consultations, by preparing questions in advance (Donnelly et al., 2008; Townsend et al., 2015).

> …to go in feeling like you at least know maybe what to expect…and you know what questions to ask. Because sometimes going to the doctor is intimidating and then they…use the medical talk and you're like, 'I don't really know what that means,' so at least if you've read a little bit, you feel more prepared and can say, 'Well, what about this?' (Rupert et al., 2014, p.324).

It was also reported that some health knowledge acquired online was beyond the expertise of GP's, causing patients to feel the need to perform research themselves to improve their self-care (Stevenson et al., 2007). Patients appreciated HCPs evaluating their internet-derived health information carefully, as it helped them achieve clarity and certainty (Sommerhalder et al., 2009). Nevertheless, Benetoli et al. (2018) reported that their respondents felt that most HCPs did not appreciate online health seeking behaviours.

5.6 Healthcare professionals' perspectives on and reactions to internet-informed patients

Patient self-diagnosis and the use of the internet for health information can also impact the HCP's role. Five qualitative (Ahluwalia et al., 2010; Townsend et al., 2015; Sommerhalder et al., 2009; Caiata-Zufferey et al., 2012; El Sherif et al., 2018) and two quantitative (Barnoy et al., 2011; Giveon et al., 2009; Barnoy et al., 2008), studies reported on these HCP's perspectives and their behaviours and reactions towards internet-informed patients. There were two major themes in relation to this: 1) HCP perceptions; and 2) HCP reactions and behaviours when dealing with internet-informed patients. These issues related to the NPT constructs of cognitive participations (relationship work); collective action (enacting work) and reflexive monitoring (appraisal work).

5.6.1 Healthcare professional's perceptions for and against people using the internet for online health information

Many HCPs perceive online health information to be useful and beneficial in terms of the way that it allows patients and the public access to a wealth of knowledge on health-related issues (Ahluwalia et al., 2010; Giveon et al., 2009; Sommerhalder et al., 2009). Two studies found that most nurses had positive attitudes (72.7%), to internet informed patients and that nurses previously exposed to consulting with internet-informed patients, adopted more positive attitudes than those who had not been exposed (Barnoy et al., 2008). Academic nurses and younger nurses reacted more comfortably to internet-informed patients compared to registered nurses and practical nurses. There was an overall positive reaction in nurses' responses to internet-informed patients (Barnoy et al., 2011; Barnoy et al., 2008). Such reactions were more commonly found in those with academic degrees and higher self-epistemic authority and confidence (Barnoy et al., 2011; Barnoy et al., 2008). Many HCPs reported that they could discuss information on a more medically grounded level with internet users than with non-internet users (Sommerhalder et al., 2009). Some HCPs felt that patients have a right to stay well-informed and that they are more satisfied this way. They also believed patients should take responsibility for their own health and be able to make decisions, provided that they can base these decisions on high-quality sources of information (Caiata-Zufferey et al., 2012).

> I think it is a good thing for patients to have access to medical information. … But this only applies to high-quality information. Because it makes people proactive. For instance, it makes people aware of insidious health problems that are often discovered too late. (Caiata-Zufferey et al., 2012, p.744).

Some HCPs, however, found online health information to be problematic, especially when patients/public interpretation of online health information was misleading or incorrect (El Sherif et al., 2018). Some physicians interpreted online health information seeking as suggesting a lack of trust in their medical expertise (Ahluwalia et al., 2010; Sommerhalder et al., 2009). There is also a known fear of losing control of the consultation with internet-informed patients and the feeling of being perceived as incompetent (Ahluwalia et al., 2010).

Internet-informed patients were also considered by some, as potentially preventing the HCP from being as effective as they could be. It can become difficult for HCPs to do their jobs efficiently as they may need to explain, interpret or suggest a conflicting opinion to the information presented from online resources (Caiata-Zufferey et al., 2012). Several HCPs also believed that the internet poses risks as patients may misinterpret information and this can also cause unnecessary medical visits (Ahluwalia et al., 2010; Caiata-Zufferey et al., 2012).

> For us, the doctors, the problem is that before starting you have to destroy. Patients come already with their theory, and you have to dismantle it. It takes some care, and then you need to start anew. (Caiata-Zufferey et al., 2012, p.742).

5.6.2 Healthcare professional's reactions and behaviours to internet-informed patients

Patients/public found reactions from HCPs such as open body language and asking open questions, made the environment more comfortable and allowed them to feel more listened to (Ahluwalia et al., 2010). Many HCPs agreed that it was important to show support to patients who used the internet for health information, but that online searching can bring associated tensions (Townsend et al., 2015). HCPs agreed on the importance of collaboration with and guidance for patients, though they struggled to find the time to do this efficiently (Townsend et al., 2015).

> I have to find ways to give them [patients] as much knowledge in a short amount of time… the amount of information that's appropriate and not excessive. (Townsend et al, 2015., p.7).

HCPs do sometimes experience anxiety around internet-informed patients, and some may find some of the information patients bring to consultations, slightly outside their area of expertise (Townsend et al., 2015).

> …because I think sometimes there's a fear that patients expect you to know everything and sometimes it's hard to admit that you don't know. (Ahluwalia et al., 2010, p.91).

5.7 Sharing online health information with healthcare professionals

There were two key subthemes here: 1) Communication, which was seen as important in maintaining good relationships between patients and HCPs. 2) Bringing online health information to the consultation, which was the decision making of whether patients would share their findings with their HCP. Seven qualitative studies (Bowes et al., 2012; Rupert et al., 2014; Townsend et al., 2015; Silver, 2015; Benetoli et al., 2018; Sommerhalder et al., 2009; Huisman et al., 2020), nine quantitative studies (Bartlett & Coulson, 2011; Imes et al., 2008; Haluza et al., 2017; Russ et al., 2011; Lu et al., 2018; Ohana & Barnoy, 2019; Singh & Banerjee, 2019; Zhang et al., 2021), and one mixed methods study (Hay et al., 2008), reported on this theme. This theme maps on to the collective action and reflexive monitoring constructs of NPT.

5.7.1 Communication

Many studies explained that enabling better communication with HCPs was one of several reasons why patients used the internet to explore health information (Bowes et al., 2012; Townsend et al., 2015; Haluza et al., 2017; Benetoli et al., 2018; Zhang et al., 2021). Townsend et al (2015) suggested that participants felt they gained more respect from HCPs after seeking health information online as they were better prepared for their consultation and could make the most of the limited time. It also allowed them to communicate and interact better based on their increased background knowledge of the health conditions involved (Bowes et al., 2012; Benetoli et al., 2018; Lu et al., 2018; Zhang et al., 2021).

> You’re trying to communicate something to this person and you want the communication to be as effective as possible, so if you can show, if you can demonstrate that you understand something then that’s going to move the whole process. (Bowes et al., 2012, p.734)

The HCPs in the study by Townsend et al (2015) agreed and said that it also allowed the consultation to be more interactive and direct as relevant questions could be asked. HCPs also felt that patient preparation promoted more focused, effective, and efficient consultations (Townsend et al., 2015).

5.7.2 Bringing online health information to the consultation

There were several factors affecting whether patients chose to disclose or not disclose their access of internet health information to their HCP. Imes et al. (2008), found that some patients did not talk to their HCP about online health information as they did not trust the sources online. Others found that there was not enough time to bring up their research during consultations (Imes et al., 2008; Benetoli et al., 2018). Several patients did not want to tread on the HCP's toes; such patients perceived they would be challenging the professional and did not want to question them or make them feel offended or intimidated by attempts to discuss online health information, thus interrupting the diagnostic process (Bowes et al., 2012; Imes et al., 2008; Sommerhalder et al., 2009). Other reasons for patients not discussing online health information research included feeling embarrassed and not wanting to be seen negatively (Bowes et al., 2012; Imes et al., 2008; Silver, 2015). Such patients were concerned about HCP's reactions to their health research online and felt that they might not be listened to or that the professionals might become dismissive or uninterested (Bowes et al., 2012; Imes et al., 2008; Hay et al., 2008; Silver, 2015; Huisman et al., 2020). In particular, patients felt that physicians would not want patients to show them how to do their jobs (Silver, 2015). In the survey by Russ et al (2011), 81% of respondents never showed their internet information to their doctors, although 77.9% were interested in their HCP referring them to appropriate online health websites. Rupert et al (2014) reported that some HCPs discouraged future online health searches by indicating that the internet was an unreliable source.

> As soon as I said I looked it up on the internet, he sort of leaned back, and sort of, [sigh] his shoulder dropped, and he, I didn't feel that he was paying as much attention to me anymore. (Bowes et al., 2012, p.735)

In contrast to these perceptions of negative reactions, some patients felt that sharing health information they found online with their HCPs could show that they had invested time and energy into the consultation (Ohana & Barnoy, 2019; Singh & Banerjee, 2019; Zhang et al., 2021). These respondents hoped this would lead to their problems being taken more seriously (Bowes et al., 2012; Benetoli et al., 2018). Positive experiences of patients sharing online health information with their doctors include all occasions when the doctor listens, acknowledges, and offers further discussion about such information (Rupert et al., 2014). Bartlett and Coulson (2011) found most participants (82.2%) to be satisfied or extremely satisfied with their HCP's reactions to their participation in online support groups, while a much smaller proportion experienced negative reactions (16.2%). They found that doctors' body language was extremely important and that even a simple smile could change the dynamic of the conversation. Patients hoped for acknowledgement of their efforts to participate in self-care (Silver, 2015). Patients also brought up internet health information where they felt their research contradicted the physician's interpretation (Sommerhalder et al., 2009). However, many patients did not use the internet to replace HCPs but rather to gain a deeper understanding of their symptoms or disease and to become more familiar with the appropriate terminology (Hay et al., 2008; Ohana & Barnoy, 2019).

> Because the fact that I actually go and research things on the internet, indicates to my GP that I'm actually serious about my health and I have an interest in it myself and I'm willing to take a bit more responsibility rather than just going in like a child, listening and being told what to do. I think it means that she's more willing to treat me as an adult. (Bowes et al., 2012, p.734)

5.8 Impact of online medical searches and diagnosis on patient-healthcare professional relationships

There were three subthemes: trust; role changing and the patient-HCP relationship. Several studies have reported on the effects of this. Ten qualitative studies (Bowes et al., 2012; Ahluwalia et al., 2010; Donnelly et al., 2008; Stevenson et al., 2007; Lee et al., 2014; Caiata-Zufferey et al., 2012; Mendes et al., 2017; Chu et al., 2017; El Sherif et al., 2018; Huisman et al., 2020), twelve quantitative studies (Imes et al., 2008; Bell et al., 2011; Barnoy et al., 2011; Giveon et al., 2009; Barnoy et al., 2008; Audrain-Pontevia & Menvielle, 2018; Lu et al., 2018; Ohana & Barnoy, 2019; Singh & Banerjee, 2019; Zhang et al., 2021), and one mixed methods study (Hay et al., 2008), reported on this theme.

5.8.1 Trust

Patients felt more trust in HCPs and hoped for discussion regarding internet health information while seeking doctors' opinions (Bowes et al., 2012; Singh & Banerjee, 2019). Patients felt more trusting towards their GP's when they were honest about their levels of knowledge, acknowledging that generalists may not know some of the highly specific information provided online (Bowes et al., 2012; Imes et al., 2008). Some HCPs deliberately showed respect when presented with online health information as a way of making sure patients felt listened to and respected, in the hope of encouraging patients to continue self-care (Ahluwalia et al., 2010). Adopting this approach allows more trust to develop between the patients and HCPs (Ahluwalia et al., 2010). One survey found that 57.5% of participants gave their physicians a perfect trust score but still used the internet after their visits to do further research (Bell et al., 2011). Overall, HCPs were found to be more trustworthy and reliable than the internet (Lee et al., 2014).

> I think that certain things should be left to doctors. That's what they are there for! Even if the Internet helps us and gives us answers, the advice

> from my doctor gives me more confidence […] I trust my doctor 100%” (Mendes et al., 2017, p.1079).

HCPs thus appear to be the most valuable source of health information (Mendes et al., 2017; Huisman et al., 2020; Singh & Banerjee, 2019). Most studies emphasised that, regardless of the popularity of online self-diagnosis, the majority of respondents valued HCP’s opinions more, understood their explanations of diagnoses better, and had more trust in them (Donnelly et al., 2008; Mendes et al., 2017; Zhang et al., 2021). However, Hay et al (2008), reported that 20% of participants went online to self-diagnose as they did not trust the diagnoses or treatment advice offered by their HCPs (Hay et al., 2008).

5.8.2 Role changing

Physicians have experienced changes in their roles since online health information has been introduced into consultations. Their new role can be described as acting as a partner to the patient, who is now more involved in both medical decision-making and consultation (Sommerhalder et al., 2009; El Sherif et al., 2018).

> That's what I’ve been experiencing by now for the last 20 years; my professional authority isn’t as sacred as it used to be. I can’t say anymore that's it, that's what I see, this is what we know and the patients are trusting and believe that we know best. It's no longer like this. (Sommerhalder et al., 2009, p.269).
>
> You just have to be really open to the fact that they’re [patients] going to tell you things you didn’t know and that’s great. “Oh, I hadn’t seen that before. That might be useful for me with other clients”. So, I definitely feel it’s more of a partnership…[like] P2 says it’s much less didactic…Like P5 said, you just put in context what they’ve already brought to the table. (Townsend et al., 2015, p.6).

5.8.3 The patient-healthcare professional relationship

Some studies showed that HCPs perceive internet health information as damaging to the patient-HCP relationship (Caiata-Zufferey et al., 2012), though other studies found that most were satisfied with internet-informed patients (Giveon et al., 2009). It was found that nurses with higher self-epistemic authority and confidence, were less influenced by online health information presented to them than those with lower self-epistemic authority (Barnoy et al., 2011). Barnoy et al. (2008) also noted that nurses with higher computer self-efficacy and lower computer apprehensiveness had more positive attitudes towards internet-informed patients.

Many participants felt that online medical searching and self-diagnosis might cause misunderstandings between them and their HCP. They did not feel they were doing this to challenge the HCP’s credibility or capability in terms of diagnosis, and most patients prioritised the HCP’s advice over the information from the internet (Singh & Banerjee, 2019). However, where the HCP’s response to health information seeking is negative and disrespectful, this can seriously impact the patient-HCP relationship, and in some cases, this can lead to a patient changing their doctor or practice (Bowes et al., 2012).

The results showed that most patients described their preferred role for HCPs as being open-minded about online health communities and online health information seeking. They expected feedback on the validity of their research and recommendations for online health communities, allowing for more engagement in the decision-making process by the patient in conjunction with the HCP (Audrain-Pontevia & Menvielle, 2018; Lu et al., 2018; Zhang et al., 2021).

> I was shocked out of my shoes the first time I went to the doctor, and the doctor came in and said, ‘Hi, my name is Steve. I'll be your doctor, and I just want you to know that you are responsible for your health, and I will make suggestions, and I would hope that you will take my suggestions, but it's up to you. Your health is your concern. Wow! I mean it changes everything. (Macias et al., 2008, p.41).

Patients tended to present information to the HCP to support the therapeutic relationship rather than to challenge it and Stevenson et al (2007) suggested that, based on this, HCPs should check all such information for validity.

> It's just helped me have…more of a conversation with my doctor rather than just being, you know, have a one-sided, just listening. I feel like I can be more active in that interaction. (Rupert et al., 2014, p.324).

Overall, the most common finding was that patients still prefer to see a HCP rather than performing online self-diagnosis and seeking internet health information. The internet is not seen as a replacement for visiting a HCP, but as offering a complimentary source of information (Donnelly et al., 2008; Mendes et al., 2017; Chu et al., 2017; Huisman et al., 2020; Ohana & Barnoy, 2019).

5.9 Chapter summary

The findings from this mixed method systematic review demonstrate that although online self-diagnosis is a growing phenomenon, the public still tend to trust the advice from a HCP over any other information source and trust in HCP's remained high. Nevertheless, the internet is viewed by patients as advantageous because of cost, accessibility, and the speed with which information can be obtained. Patients found HCP's to be the most valued source of health information but found the internet to be a useful complementary tool.

The following chapter presents the next phase of the findings reporting the analysis of heart failure online health forums.

Chapter 6 – Findings: Heart Failure Online Health Forums

6.1 Introduction

This chapter presents the findings from phase two of the research, exploring heart failure online health forums reporting on themes from the same qualitative data set using a critical realist approach. This phase divides into two parts, the first analysing the posts made on these forums and the second analysing the responses to these posts.

The research is concerned about real people and real services and critical realism has a philosophical stance in approaching the study in a real manner while interacting phenomena that involves both individuals and society. It recognises the importance of both the individual and the influential structures and cultures of society. Phenomena such as an individual's perceptions and actions, team culture and participation and policy are all contributors to the development of improved systems of care. In line with this research, I sought to understand the types of information people were seeking on online health forums; the role of peer-to-peer healthcare; how people's decision-making processes are influenced by online health forums; and how they apply this information to real life.

A thematic analysis was conducted (Braun & Clarke, 2012) and themes were mapped onto the core constructs of the NPT framework (May & Finch, 2009). The rest of the chapter is divided into the aforementioned two parts with the following research questions addressed in each part:

Part one research questions:

RQ4. *How does online health information seeking shape people's decision-making?*

RQ5. *What information do people concerned about heart failure seek when using online health forums for self-diagnosis?*

RQ6. *How does the use of online health forums, in the context of heart failure, affect people's trust in HCPs?*

Part two research questions:

RQ7. *How evidence based is the diagnostic advice provided from heart failure online health forums and what are the types of information responses provided on them?*

RQ8. *What are the public and HCP perceptions of online health forums and social media support groups as an information source?*

6.2 Part One: Understanding the use of online health forums

6.2.1 Posts

As explained in Chapter Four, ten forums were used for analysis after the search and selection process was completed. From these, 204 specific posts were downloaded and analysed. Four online health forums were identified by Google, six by Yahoo and Bing did not identify any additional online health forums (Table 6-1). Gender was specified in 54/204 posts. Of these, 28 were females, and 26 males. Ninety-two posts specified the participants' age (see Table 6-1). Most posts were written by the individual themselves (n=182), and others were written for advice about relatives (n=22).

Table 6-1: Search engine results

Search engine	**Search term**	**# of results**	**Excluded**	**Reasons for exclusion**	**Eligible**
Google	Online health discussion forums for heart failure	18	15	Information only website: 7 Online health forums require login details: 3 Journal article: 3 Newspaper article: 1 Online health forum not focused on heart conditions: 1	3 From page one: 3 From page two: 0

	Heart failure online support forums	20	18	Information websites: 11 Online health forum requires login details: 5 Not relevant to search criteria: 1 Journal article: 1	2 From page one: 2 From page two: 0
Yahoo	Online health discussion forums for heart failure	18	7	Information websites: 2 Online health forum requires login details: 2 Online health forums not about humans: 2 Online health forums for healthcare professionals: 1	11 From page one: 7 From page two: 4
	Heart failure online support forums	18	12	Information websites only: 8 Online health forums require login details: 3 Online health forum not focused on heart conditions: 1	6 From page one: 3 From page two: 3
Bing	Online health discussion forums for heart failure	20	9	Information website: 3 Online health forum requires login details: 3 Online health forum for healthcare professionals: 1 Online health forums not about humans: 1 Not relevant to search criteria: 1	11 From page one: 6 From page two: 5
	Heart failure online support forums	19	9	Information website: 6 Online health forum requires login details: 2 Online health forum not focused on heart conditions: 1	10 From page one: 5 From page two: 5

Table 6-2: Frequency count of posts per age range

Age:	No. of posts
18-24	35
25-29	28
30-35	13
36-39	4
40-49	8
>50	4

6.2.3 Data analysis

Each item of extracted data was coded independently through thematic analysis. The codes were analysed in a framework and then mapped onto the constructs of NPT (Table 6-3).

Table 6-3: NPT coding frame (based on Farnood et al., 2021)

Coherence (Sense-Making Work)	Cognitive Participation (Relationship Work)	Collective Action (Enacting Work)	Reflexive Monitoring (Appraisal Work)
Differentiation	**Initiation**	**Interactional workability**	**Systemization**
Using online health forums and communities to gain information and self-diagnose.	The peer-to-peer engagement within the groups and seeking assurance.	Communicating complex health issues and experiences online with peers.	Determining the benefits and risks of online self-diagnosis and health information seeking on online health forums.
Communal specification	**Enrolment**	**Relational integration**	**Communal appraisal**
Asking follow-up questions to understand the individuals situation/experience, to increase	Peers' reactions and behaviours towards other peers' comments. Communicating effectively to ensure a	The influence of sharing health advice with others and gaining support, and the impact this has on the individual. Maintaining	Working together on the internet to determine and evaluate the value of certain treatments. To aid decision-

understanding and build a response.	resolution and minimising conflict of opinions.	a level of confidence and accountability to continue using the online forums.	making on treatments.
Individual specification	**Legitimation**	**Skillset workability**	**Individual appraisal**
People achieving an understanding of their diagnosis and its implications through health information gained via the internet through peers.	Working together in responses to reach a conclusion. Sharing similar experiences to ensure relevance and offer opinions. Justifying concerns and difficulties.	The effect of using online information on roles and responsibilities of members of the public or HCPs. The impact online information has on the decision-making process.	Collecting and distributing information on the internet to determine how effective their treatment is, to provide or gain a diagnosis and to help appraise their HCPs advice.
Internalization	**Activation**	**Contextual integration**	**Reconfiguration**
Peoples understanding of using the internet to self-diagnose and knowing if this is their preference or if they value the role of the HCP consultations instead.	Communicating effectively with peers by expressing relatability and assurance.	Integrating online self-diagnosis and health information into social circumstances. Recommending the individual to seek professional medical attention or to be seen by an HCP. Offering health advice by referring to other online resources.	Individuals decision-making process of how effective online health forums are for diagnosing and seeking health information for heart failure. The impact this has on relationships with their HCP.

6.3 Presentation of Findings

Three major themes (information and support needs, online diagnosis, and relationship with the HCP) and several subthemes were identified from the analysis (Table 6-4). Each theme was mapped onto the core constructs of the NPT framework. Table 6-5 provides a frequency count of each discussion forum theme.

NPT has helped bring focus to the important aspects of the information people concerned about heart failure seek on online health forums and how this shapes decision making, trust and interactions with HCPs through information and support needs (coherence – sense-making work; collective action – enacting work; cognitive participation – relationship work), online diagnosis (coherence – sense-making work; cognitive participation – relationship work), and relationships with HCPs (cognitive participation – relationship work; collective action – enacting work; reflexive monitoring - appraisal work).

Table 6-4: List of themes and sub-themes

Themes	**Sub-themes**
Information and support needs	- Discussion of results - Support - Heart failure diagnosis and implications for life expectancy - Health insurance - Medications - Lifestyle, diet and exercise - Symptoms of heart failure
Online diagnosis	- Self-diagnosing online - Internet vs healthcare professional diagnosis
Relationship with HCPs	- Anxiety - Time - Behaviour - Communication

Table 6-5: Frequency count of discussion forum themes

Discussion forum themes	**Frequency of mentions**
Information and support needs	165
Online diagnosis	41
Relationship with HCPs	132

6.4 Information and support needs

This theme describes the types of information sought by people from online health forums. This covered several topics: discussion of results; support; the life expectancy of people diagnosed with heart failure; health insurance; medications; lifestyle, diet and exercise; and symptoms of heart failure. These relate mostly to the NPT theoretical constructs of coherence (sense-making work) and collective action (enacting work). However, some of the issues raised related to cognitive participation (relationship work), when people were seeking advice and supportive information.

6.4.1 Discussion of results

People often failed to adequately understand the results of tests or investigations, sometimes this was attributed to poor communication with HCPs. Frequently, people posted their doctor's summary and sought input from other forum members to determine its meaning. They sought to gain a better understanding from the online health forums. It appeared that people often felt HCPs did not have enough time to adequately explain results; they did not understand the discussion with the HCPs; or the results were to be discussed in a follow-up meeting.

This was reported several times when the individual was newly diagnosed with heart failure and was given no further explanation as to the meaning of the severity of their test results. They explained as a newly diagnosed individual, they were unsure of the meaning of the medical terms associated with their new diagnosis and felt they had not sought clarity from their HCPs to explain this.

> I have just been diagnosed with CHF. I have my doctor's notes, but nobody has really explained what's going on. What does CHF-D 1/4 Mean on my Doctors Medical Summary?

6.4.2 Support

Many people used online health forums to find support. This was particularly true for those who were diagnosed with heart failure and struggled to cope with the impact it had on their lives. Online health forums seemed to help people find a platform to share similar experiences and gain support when talking to other people living with the same condition. This seemed beneficial since some individuals reported finding it difficult to discuss their condition with family and loved ones and the presence of online health forums contributed to them feeling they were not alone.

People expressed that their heart condition made them feel isolated from others. They did not feel others would truly understand the experiences they were facing. Many people used online health forums to find support from peers who had a true understanding of the depths of their experiences.

> I'm 34 have been diagnosed with heart failure for less than a year… Does anyone else feel alone even though you have a partner?... In need of support.

6.4.3 Heart failure diagnosis and implications for life expectancy

Following a heart failure diagnosis, the life expectancy forecast represented the most frequently asked question. There were examples of people who had not yet been diagnosed but were concerned about future diagnoses and it became evident that this was a popular question to ask online. Usually, people sought this information to prepare themselves for what they may hear from the HCP.

It also appeared that the term of the condition ‘heart failure’, led users to believe this would be the result of a drastically short life. They reported not understanding the medical terms associated with heart failure but feared the worst with the diagnosis. It seemed the time period between receiving the diagnosis and waiting for the follow-up appointment was the most common time this question was asked, and people’s fears were at the highest.

Some people were seeking advice on behalf of their relatives - sharing their concerns and enquiring how long other peers felt their relative’s life expectancy after diagnosis would be.

> One week in hospital and my symptoms have worsened, I can’t walk nearly as much as I could. I’ve had MRIs, ultrasounds, ECHO, X-rays and nothing

> seems to appear as a cause. I don't smoke or drink. What can I expect to hear about my life expectancy?

6.4.4 Health insurance

Online health forums were one of the primary options for people who are not covered by health insurance and living in countries where there is not universal access to free healthcare. In these scenarios, individuals searched the internet and self-diagnosed by utilising online health forums to enable them to decide if further medical attention should be sought. Online health forums had the advantage of being free and accessible at any given time and provide an important source of information for those not covered by health insurance. People also queried if their health insurance would cover the consultations and treatments they needed.

> I have no idea how to get diagnosed or cleared without any health insurance, but I am very concerned, and I guess, just looking for any advice or similar experiences.

6.4.5 Medications

When already diagnosed with heart failure, individuals sought information on their medication side-effects. People shared the symptoms they experienced since starting to take the medication, looking for advice. In addition, people posted questioning the reasoning behind an increase in medications or why dosages may be changed to check the accuracy of the advice they received.

Furthermore, people regularly posted when they were starting a new heart medication and asked others what their experiences of this medication were and any potential side-effects they may face.

Several posts were from relatives of elderly people with heart failure expressing concerns that their relative had been given several new medications but were unable to understand why they were taking them. This led the relative of the person with heart failure to use online health forums to ask questions about the medication such as why they were put on it, is the dosage correct and information about the side-effects of each medication.

> They've given him a fair few kinds of medication to take and have sent him home with his discharge notes but he doesn’t know what they are.

6.4.6 Lifestyle, diet and exercise

Usually, individuals recently diagnosed with heart failure wanted to learn more about their condition and how it would affect their lifestyle. They related easily with people who received the same diagnosis, when communicating with them. Many posts concerned the necessary lifestyle changes to embrace for preventing heart failure exacerbations.

> I'm in cardiac rehab, exercise on my own, and my diet's much better. But the first cardiologist was a real downer, saying he didn't see improvements in my future. The second was better, encouraging cycling and work. How can my ejection fraction be improved?

6.4.7 Symptoms of heart failure

Breathlessness and exhaustion were the most commonly described symptoms of heart failure. Other symptoms included chest pain, heart pounding, palpitations, dizziness and swollen legs. People described heart failure symptoms in numerous ways. These are recorded in Table 6-6 and reported in the lay language that individuals used for describing their symptoms. In most cases, posts involved undiagnosed individuals seeking a diagnosis, or those anxious about heart failure symptoms. In addition, individuals posted that they experienced such symptoms, while awaiting test results.

People found a connection through sharing symptom experiences on online forums which helped to reduce isolation. In extreme circumstances, some individuals complained that they felt they had to choose between managing their symptoms or possible death.

> I am tired all the time and very breathless… also just had some swelling to my ankles. I am not overweight, also just started to get very heavy legs while walking upstairs… I am so worried i have heart failure.

Table 6-6: Description of symptoms to diagnose heart failure

Description of symptoms to diagnose heart failure	**Number of posts with mentions**
Breathlessness / Shortness of breath	39
Chest pain/ chest pressure/ chest tightness/ weight on chest/ chest discomfort. Heavy arrhythmias/ sharp shooting pains	37
Dizziness / feeling faint / lightheaded/ falling backwards/ passing out/ disorientated	24
Exhaustion /fatigue/tired/weak/low energy	23
Palpitations	20
Fast heart rate / tachycardia / heart racing / elevated heart rate / pounding heart	11
Pain down arm	8
Stomach bloats/ stomach pain/ stomach disorders/ abdominal pain/ abdominal discomfort/swollen stomach	7
Sweating / hot / clammy	6
Headaches/ head pressure	6
Nausea / feeling sick/ lack of appetite	6
Dry cough/ chronic cough/ coughing/ cough with fluid	6
Legs swelling/ puffy legs	5
Feet swelling	4
Ankle swelling	4
Shoulder pain	4
Anxiety/ panic attack	3
Heart flutters	3
Neck pain	3
Jaw ache	3
Low heart rate / slowed heart rate	3
Floaters in vision/ blurry vision/ left eye waters	3
Heavy legs/ pain in leg	3
Pain in armpit	2
Flu	2
Joint pains	2

Irregular heartbeat/ missing beats	2
Cold hands	1

6.5 Online diagnosis

Online health forums were used to guess a diagnosis from peers' experiences, to understand signs and symptoms, to discuss heart failure, to garner support and to aid decision-making (Figure 6-1). This section is divided into two sub-themes: self-diagnosing online and internet vs HCP diagnosis. These issues related to the NPT constructs of coherence (sense-making work) and cognitive participation (relationship work).

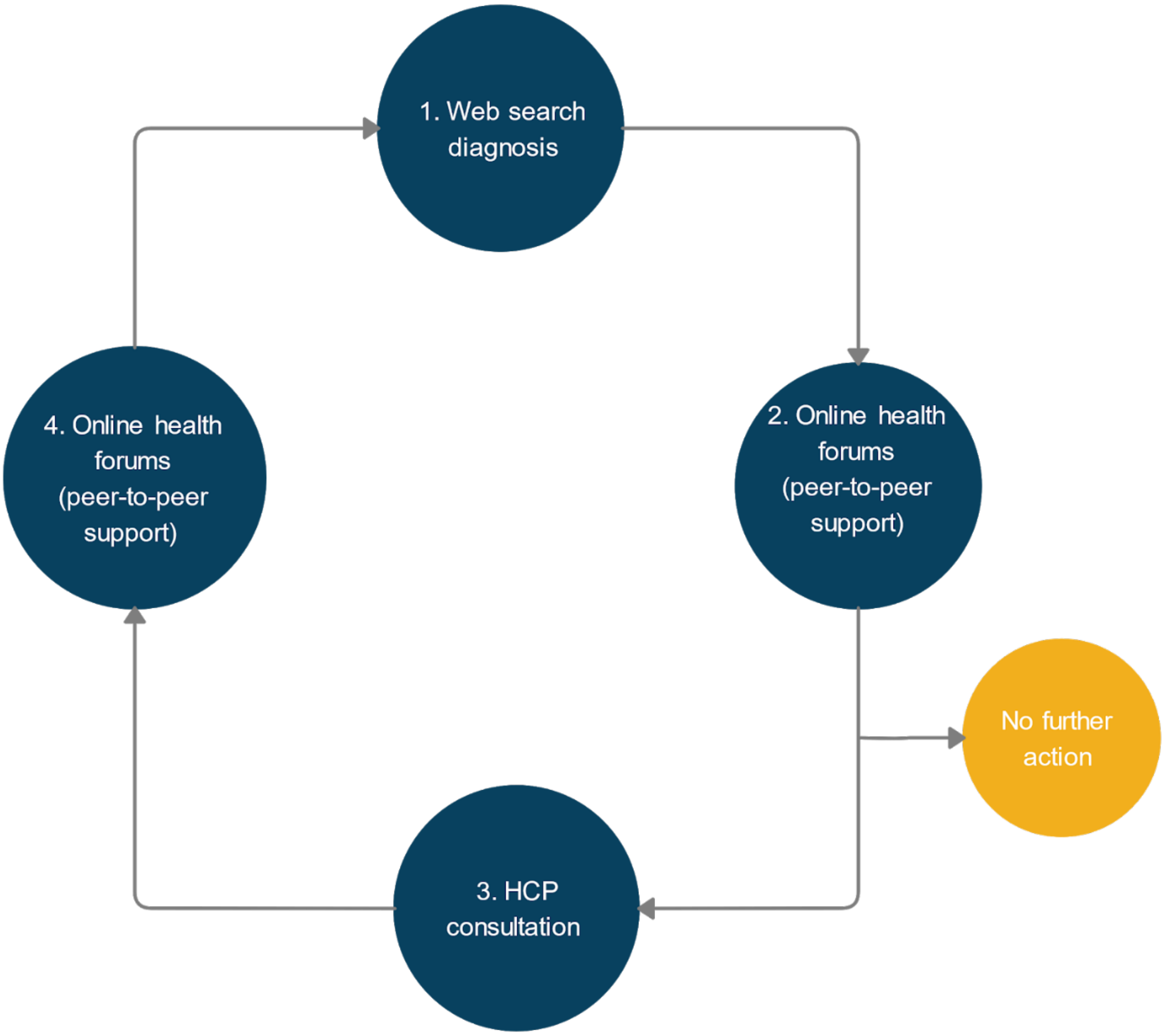


Figure 6-1:Online diagnosis decision making model

6.5.1 Self-diagnosing online

People often became concerned about navigating web sources to find online information and misunderstanding it. Many people reported searching the web prior to using the discussion forums. Online health forums were either used during the second stage of the diagnostic process (after web searching), or by those who had already received a heart failure diagnosis from a HCP when they were seeking clarification about issues. Additionally, they were used if an individual had not yet received a diagnosis or was unhappy with information received from HCPs.

Peer-to-peer diagnosis on online health forums offered a more personalised approach. The peer-to-peer diagnostic process was typically used to diagnose signs and symptoms; awaiting results from tests; concerns for family members; and people who have either been recently diagnosed or already have heart failure to connect with others in similar circumstances and exchange experiences. This allowed a community to develop online. People often reported sharing similar experiences via online health forums was helpful and reassuring.

Online health forums contributed to the individuals' decision-making process as they served as a tool to gain information that would inform next steps (Figure 6-1).

> I have been googling my symptoms (i.e., Doing just what the doctors seem to hate people doing!) and I seem to have all the symptoms of either heart valve problems or heart failure.

6.5.2 Internet vs HCP diagnosis

After web searching, people may decide to seek medical attention or be satisfied with the information they gained. However, people sometimes used the internet after a healthcare consultation, and received answers different to the HCP's diagnosis. This led to individuals becoming confused and referring back to online health forums for further guidance.

> I don't see the cardiologist until Thursday so of course, I Googled Impaired Left Ventricular Relaxation and all I see is I have heart disease, but my doctor is acting like it's nothing.

6.6 Relationship with HCPs

This can be subdivided into four subthemes: anxiety, time, behaviour and communication. Anxiety symptoms can be very similar to the ones displayed in heart conditions and people could often seek advice regarding whether their symptoms were “in my head or my heart”. Others sought advice as they lacked confidence in the HCP. This theme maps onto the cognitive participation (relationship work), collective action (operationalisation work) and reflexive monitoring (appraisal) constructs of NPT.

6.6.1 Anxiety

Many people posting on online health forums declared that they already had self-diagnosed anxiety but were convinced there was more to what they were experiencing. Interestingly, when they received a favourable diagnosis from their HCP (they do not have heart failure), this was insufficient to appease them. Individuals could become further distressed, as they felt no one was believing them.

Several posts were from individuals who had consulted with a HCP and received normal test results but still believed they were suffering from heart issues. Some individuals requested repeat tests several times, while others sought a second professional opinion. It was frequently mentioned that people saw multiple doctors due to a lack of trust and because of their persistent scepticism about test results.

Some people, having researched their symptoms and concluded that they have heart failure, perceived that they were being written off and not taken seriously and grew to distrust their HCP.

> I am a 21-year-old female with severe health anxiety, ptsd, and a history of heart palpitations… I dont want to have chf. I am so afraid of it and dont want to die early.

6.6.2 Time

People often used online health forums when they felt they did not have enough time within the HCP consultation to address all their concerns. They felt there was only enough time for the HCP assessment and not enough for the person receiving the diagnosis to process the information and ask appropriate questions. This was a common reason for using online health forums, to fill information gaps due to the time constraints within the consultation.

> I have the results and I have asked him to go over them with me. He said he has so many patients that he doesn't have time… I've not had any other doctor unwilling to tell me if my results are good or bad or anything. Is there a site I can find that can tell me what these results mean?

6.6.3 Behaviour

Some people perceived that they were not being taken seriously by their HCPs. Individuals sensed that they were becoming an annoyance to the HCP, who were increasingly impatient with their problems and suspect that their HCP may not believe their problems anymore. People reported that when their HCP responded negatively towards them, it triggered distrust and conflict, which led them to online health forums to seek alternative advice.

HCP’s behaviour towards individuals was shown to have an impact on trust within the relationship. Many people who use online health forums went to this source either due to a lack of trust with their HCP (as described above), or a lack of understanding of the information they were given. As people engaged with other peers, it appeared possible that it could cause further distrust as they hear other users’ negative experiences.

> Doctors shove me to the waiting room now because they don't think it’s serious. But its serious to me.

6.6.4 Communication

Several posts stated that HCPs were not providing people with the information they desired and communicating with them the way they hoped for, which led them to access online health forums. Reportedly, HCPs did not explain the results clearly. In addition, others felt unable to talk to their HCP, because they kept receiving an anxiety diagnosis, even though they were certain it was not.

After a heart failure diagnosis, some individuals felt they were not given sufficient information regarding how this would influence their lives. Some felt that their HCPs were vague and, when diagnosed, they sensed that some HCPs were not forthcoming with information about the severity of their condition.

> When I asked what this meant he was a bit vague and when I asked how long a person can live with this, he was even more vague.

6.7 Part Two: A response analysis of the peer-to-peer health information provided on online heart failure forums

6.7.1 Screening

Screening for phases one and two were conducted together and share the same method.

6.7.2 Data collection

The total number of responses collected for analysis was 639 (from 204 original posts). In some threads, each member posted on average two or three comments, although some members were particularly active (usually the original poster). The frequency count of response within each theme and sub-theme are presented in Table 6-7.

Gender was specified in 51/639 of the response posts. Of these, 39 were females (76%) and 12 males (24%). The members ranged from people seeking a diagnosis, to those already diagnosed sharing their experiences, providing advice or gaining support. Geographical location was mentioned in 49/639 of the response posts (see Table 6-8).

Table 6-7: Frequency count of responses in each theme

No. of responses in each theme	**No. of responses in each sub-theme**
Diagnostic responses (n=298) Collective Action (CA) & Reflexive Monitoring (RM)	- Evidence-based nature of the diagnostic responses (n=162) - Signposting services (n=136)
Experiential (n=135) Cognitive Participation (CP)	- Sharing personal experiences (n=68) - Experiential supportive information (n=67)
Informational (n=101)	- Finding out more information (n=59) - Giving advice (n=35)

Coherence (CO) & Cognitive Participation (CP)	- Advising against internet (n=7)
Peer relations (n=84) Cognitive Participation (CP) & Reflexive Monitoring (RM)	- Peer conflict (n=14) - Support (n=70)
Relationship with HCPs (n=21) Cognitive Participation (CP) & Reflexive Monitoring (RM)	- Distrust/conflict with HCPs (n=16) - Supportive of HCPs (n=5)

Table 6-8: Location of responders

Country	No. of responses
UK	N=16 (33%)
USA	N=16 (33%)
Australia	N=10 (20%)
Canada	N=4 (8%)
France	N=2 (4%)
Pakistan	N=1 (2%)

6.7.3 Data analysis

Each item of extracted data was coded independently through thematic analysis. The codes were analysed and then mapped onto the constructs of NPT (Table 6-3). Diagnostic responses were assessed for their quality of evidence by using the SIGN (SIGN, 2016) and NICE (NICE, 2018) guidelines as the gold standard to judge the quality of information provided. The hierarchy of evidence based upon the John Hopkins nursing evidence-based practice guidelines (Dang & Dearholt, 2019), was adopted to assess the levels and quality of evidence provided in the responses, as presented in Chapter Four.

6.8 Presentation of Findings

Five broad themes with sub-themes were identified: diagnostic responses, experiential, informational, peer relations and relationship with HCPs. Each theme was mapped onto the core constructs of the NPT framework. The themes have been illustrated with paraphrased extracts from the response posts. Direct quotations have been limited as these may allow the data to be tracked to the original source which will compromise anonymity. Therefore, only one quotation per sub-theme has been included. The themes have been developed from quotations across the sources of data, highlighting similar topic areas identified from the heart failure forums.

NPT has helped highlight the important aspects of the types of information people seek on heart failure online health forums: diagnostic advice (collective action – enacting work; reflexive monitoring – appraisal work), support and sharing experiences (cognitive participation – relationship work), seeking information (coherence – sense-making work; cognitive participation – relationship work), building peer relationships (cognitive participation – relationship work; reflexive monitoring (appraisal work), and relationships with HCPs (cognitive participation – relationship work; reflexive monitoring – appraisal work).

6.9 Diagnostic responses

A large proportion of the responses were of a diagnostic nature. Direct diagnostic responses (n=298) were compared against the NICE and SIGN guidelines for quality of evidence based upon the John Hopkins evidence-based practice guideline (Table 6-9) (Dang & Dearholt, 2017). Figure 6-2 provides a detailed illustration of the obtained results. These relate mostly to the NPT theoretical construct of collective action (enacting work) as this is the process of communicating health information with peers and recommending resources and information. The reflexive monitoring construct (appraisal work) is also related to this theme as it involves the distribution of information that leads to decision-making (Table 6-3).

Table 6-9: Quality of evidence criteria and frequency count

Total number of responses that were diagnostic	N= 298
Level 1) High quality evidence: Aligned with SIGN or NICE guidelines for heart failure – responses that contained information that can be found in the SIGN or NICE clinical guidelines for heart failure (does not have to include reference to guidelines).	N=15 (5%)
Level 2) Good quality evidence: Responses that included information that was supported by a mix of high- and moderate-quality evidence such as the BHF.	N=19 (6%)
Level 3) Evidence-based: Responses that included information that were not in the guidelines but were supported by some reliable sources but appeared inconclusive.	N=0 (0%)
Level 4) Opinion: No advice given but opinion provided to help inform the next steps by signposting users to their HCP or other information sources.	N=136 (46%)
Level 5a) Low quality (experiential): Responses that offered advice based on an individual's personal experience but included no evidence.	N=29 (10%)
Level 5b) Low quality (lack of evidence): Advice provided that was not deemed potentially dangerous but had no supporting evidence.	N=70 (23%)
Level 5c) Non evidence-based and potentially harmful: Includes responses	N=29 (10%)

including information that is inconsistent with the national guidelines or high-quality/good evidence of best practice and may be harmful.	

6.9.1 Evidence-based nature of the responses

Only 5% (n=15) of the obtained responses were evidence-based and aligned with the SIGN and NICE guidelines. Another 6% (n=19) presented information that was available on the BHF website or partly evidence-based information. Importantly, 10% (n=29) of the responses were non-evidence based and potentially harmful. No responses (0%) provided inconclusive evidence. The majority of responses lay in between low-quality categories and opinions, for example: experiential responses 10% (n=29) and provided innocuous advice unsupported by clinical evidence (23%, n=70) or signposting services 46% (n=136). Table 6-9 presents the levels of evidence for responses. Figure 6-2 illustrates the types of responses.

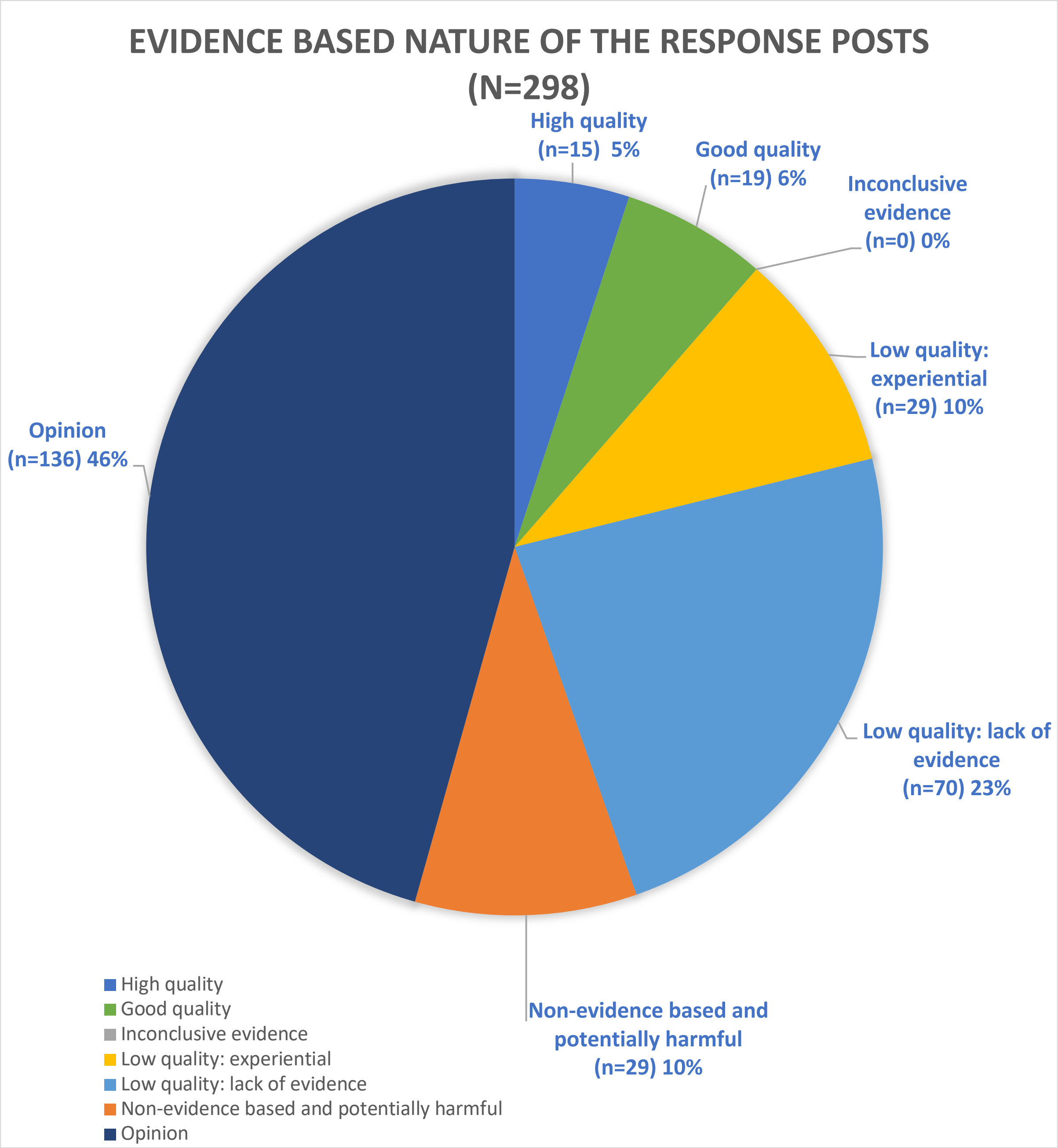


Figure 6-2: Evidence based nature of the response posts

Many responders stated they were not HCPs but advised the individual to seek medical attention. Within these replies, a medical diagnosis or opinion was also given. This was deemed to be evidence-based, if it provided information compatible with that found within the NICE or SIGN guidelines. In addition, the offered advice was considered as evidence-based if reported on the BHF website, even though it could not be found within NICE or SIGN guidelines.

> Sorry to read about what you are dealing with. I would suggest visiting your primary care doctor and ask to be referred to a cardiologist. Also, many things can cause chest pain that are not heart related.

Very few posts shared information about research, and none mentioned ongoing research. This may suggest that research sources are not rapidly and easily accessible to the public. Diagnostic advice was offered based on their own experiences of the signs, symptoms or questions asked by the user (10%). While this type of diagnostic advice may be supportive to the posting individual, it does not represent good and reliable advice since no scientific evidence was shared.

> It sounds like the same thing I had. The doctors called it congestive heart failure. Sadly, I need to say if this is the case, you will need a lot of heart care.

Non-evidence based and potentially harmful replies included those offering a confirmed diagnosis to the individual (10%). This diagnosis was incorrect, not supported by information included within the NICE, SIGN or BHF guidelines, and did not contain any underpinning evidence to support the advice given. Many posts signposted users to their HCP or other web sources including informational websites, other more appropriate online health forums and charity or university websites. Out of 46 website suggestions, 41 were deemed reliable, and 5 were unreliable sources and potentially dangerous.

6.9.2 Signposting services

The majority of responses (n=136, 46%) provided opinions that informed the posting individual to take action and visit their HCP (n=90) or to visit other web sources (n=46) and were graded as level four evidence (Table 6-9), as they provided no evidence but were responses based on opinion (Figure 6-2). Usually, this suggestion was given when the responder perceived that the query departed significantly from their knowledge spectrum and required specialist advice. In addition, the responders acknowledged their inability to provide sound diagnostic suggestions for individuals perceived to be in need of urgent attention and appropriate testing to determine their cause for concern. When individuals experienced high levels of anxiety, usually responders offered psychological support simultaneously suggesting they seek professional help to receive appropriate care to ease their worries.

> You really need to talk to the heart failure team for a detailed prognosis as there are various types of heart failure. They may also be able to advise on counselling if you are struggling to cope.

When professional help was suggested, a variety of terminologies were used, and different HCP types were recommended. Most responders urged the individual to visit a doctor. A visit to the cardiologist or doctor represented the most frequent recommendation, followed closely by an appointment with the GP/primary care practitioner. While mentioned, nurses, even heart failure specialist nurses, were not as commonly endorsed. Other recommended services included pharmacists, social services and counsellors. When the responder perceived the presented scenario to be an emergency situation, hospital services were strongly advised. Different terminologies were used for hospital settings, including going to the Emergency Room or Accident and Emergency, based on the responder's geographical location (see Table 6-10).

> Sounds like you should go to the emergency room for a second opinion.

Table 6-10: Frequency of mentions of HCPs and terminologies used

Healthcare Professionals	**Frequency of mentions**
Doctors	
Cardiologist	25
Doctor	25
General Practitioner (GP)	7
Primary Care Practitioner (PCP)	3
Physician	3
Primary care doctor	2
Neurologist	1
GI doctor	1
Nurses	
Heart Failure Nurse	2
Nurse	1
BHF nurse	1
Other healthcare professions	
Heart failure team	1
Social services	1
Pharmacist	1
Counsellor	1
Hospital services	
Emergency room	7
Hospital	6
Accident & Emergency (A&E)	2

Consistently, most replies offered advice but simultaneously recommended that the person should visit their HCP for urgent attention, testing, and further support or to receive the appropriate care.

> Can I suggest you go back again, and again if they are not listening? The blood pressure figures you have quoted are extremely low. The heart rate you quoted is very slow. An athlete who is very fit, they can get down to those kinds of numbers. Something isn't right, seek medical assistance and advice is my advice

Website content and link reliability were analysed in the event of web sources being suggested through the diagnostic advice process. A total of 46 replies recommended other web sources. It was discovered that 41 of these websites were reliable (Figure 6-3) and 5 were unreliable (Figure 6-8).

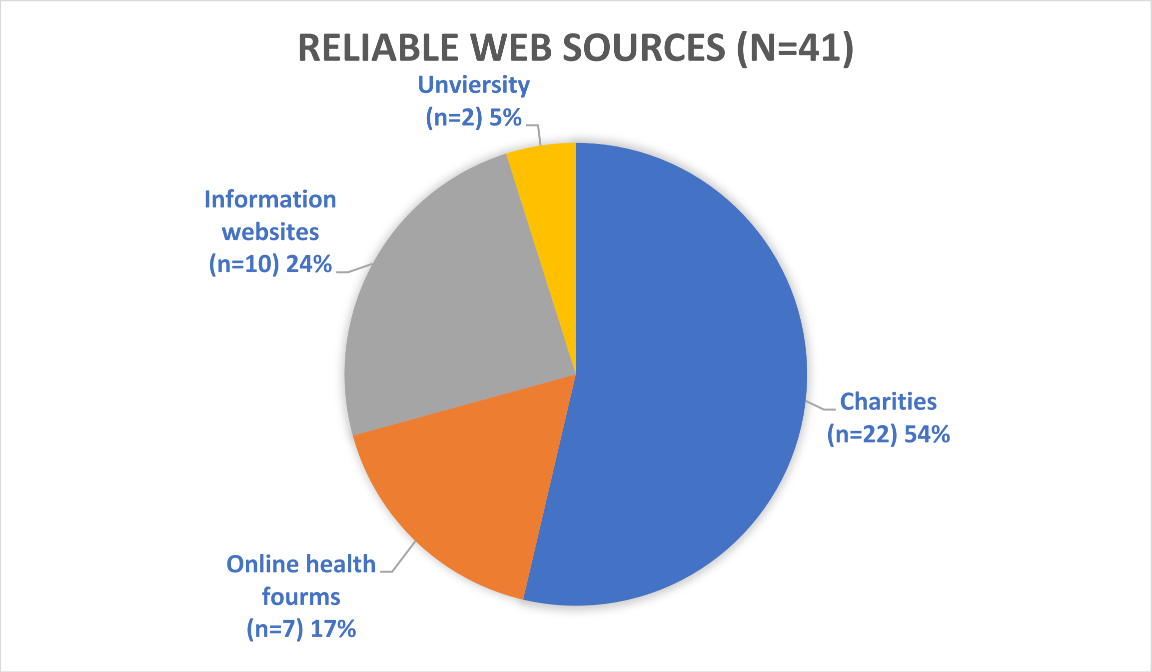


Figure 6-3: Reliable web sources data

Charity websites (n=22), such as the American Heart Association or BHF were the most frequently recommended (Figure 6-4). Individuals were also directed towards other online health forums (n=7), presumed to be more suitable for their needs (Figure 6-5), information websites (n=10) such as NHS (Figure 6-6), and university web links (n=2) (Figure 6-6).

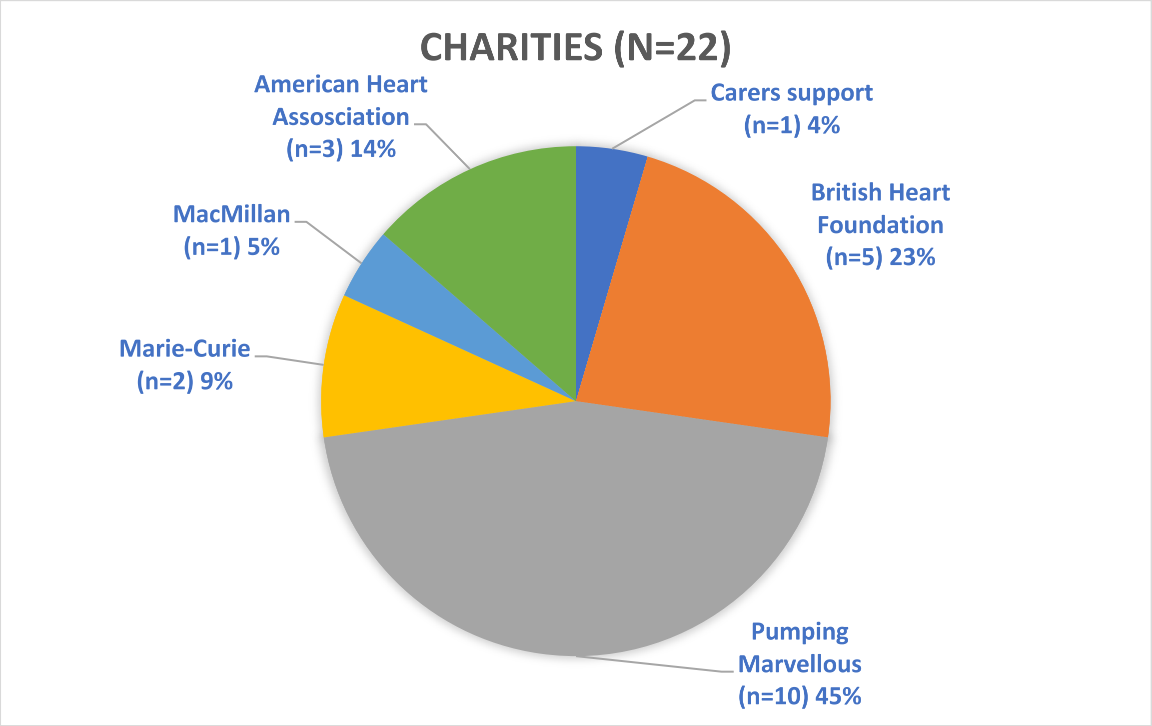


Figure 6-4: Suggested charity web sources

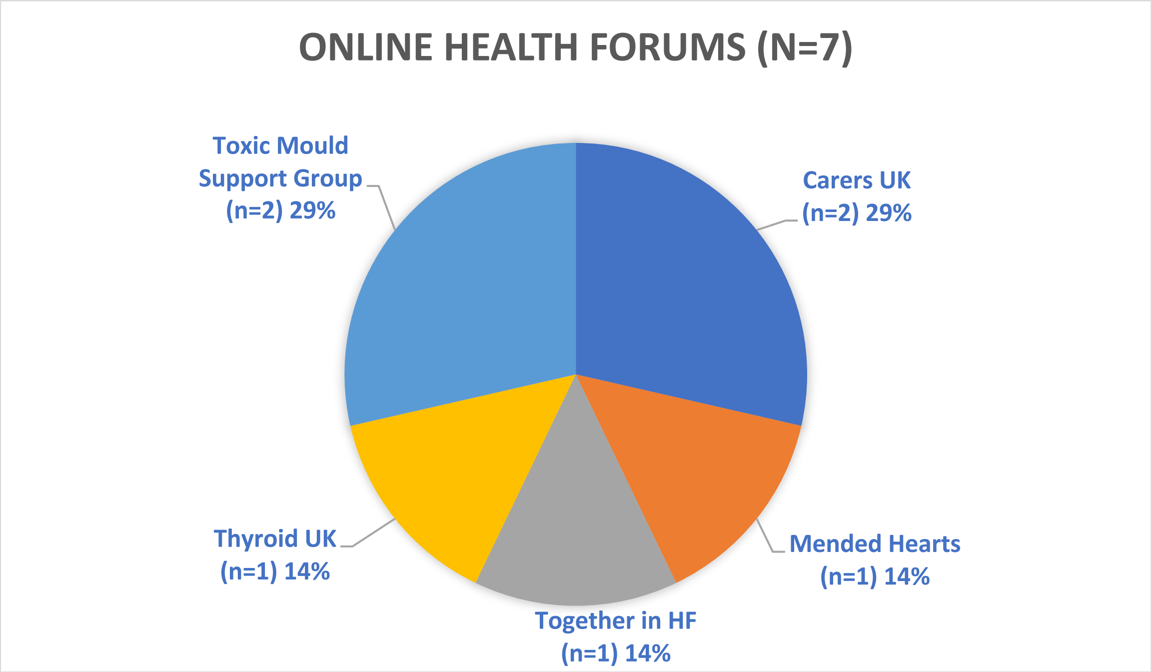


Figure 6-5: Suggested online health forum sources

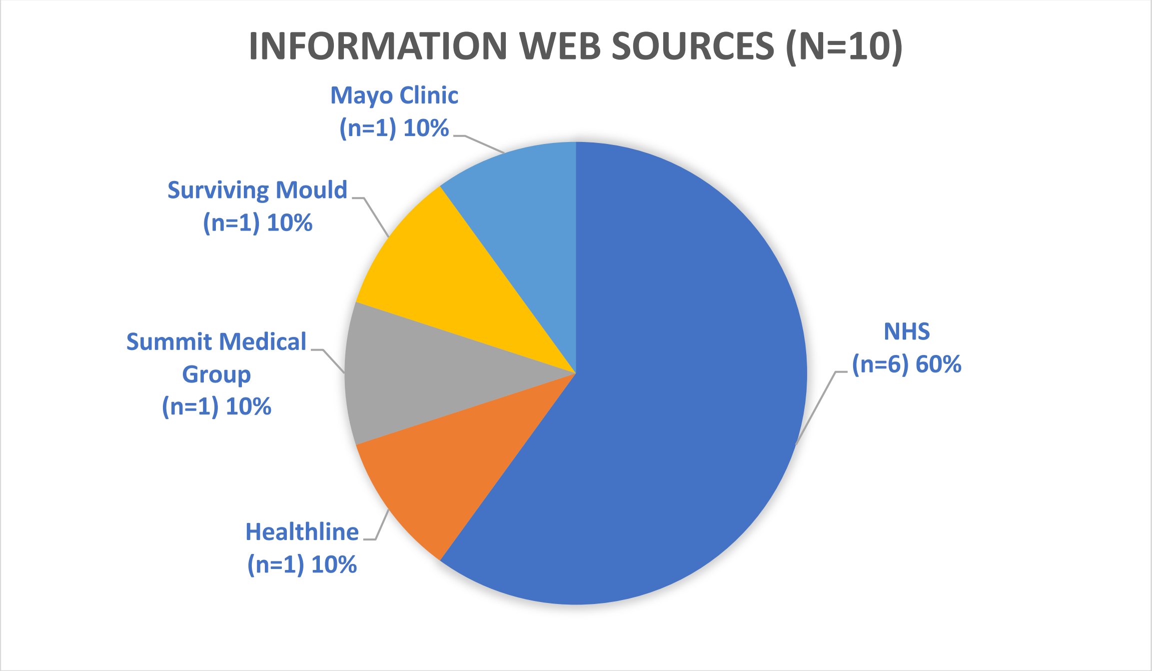


Figure 6-6: Suggested online information sources

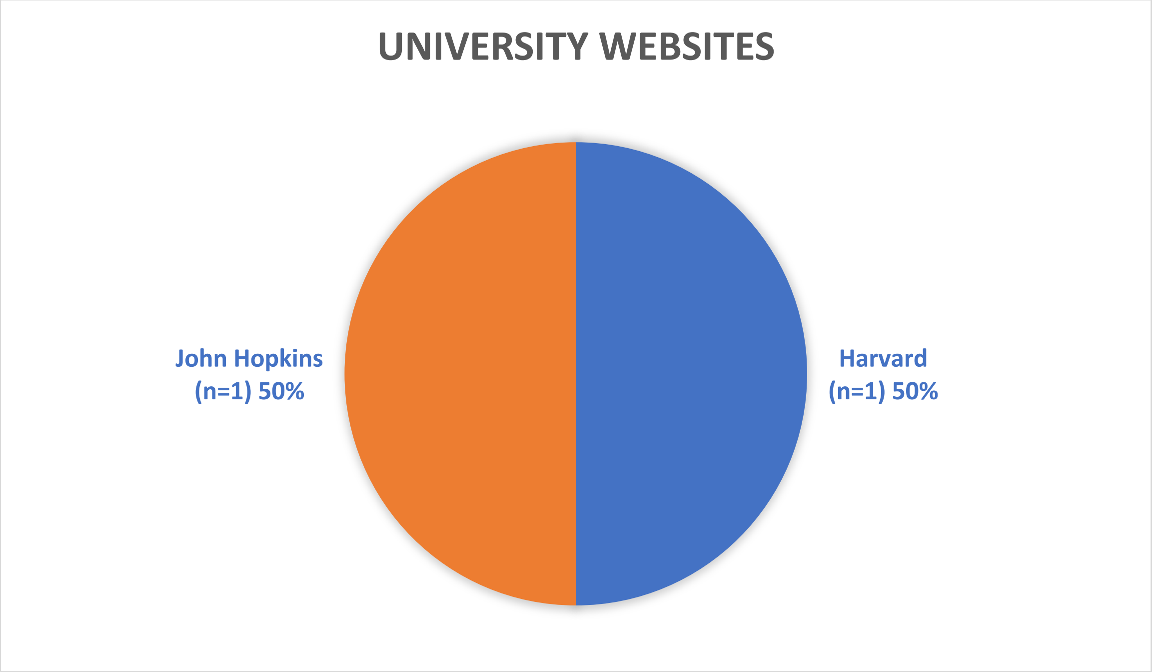


Figure 6-7: Suggested university online sources

Unreliable sources included an uncredited YouTube link for a channel belonging to an unknown user (n=1), and a Wikipedia page (n=1), untrustworthy by definition since the reported information is subject to change implemented by anyone. Other unreliable sources included web links that did not work or pages that could not be found (n=3).

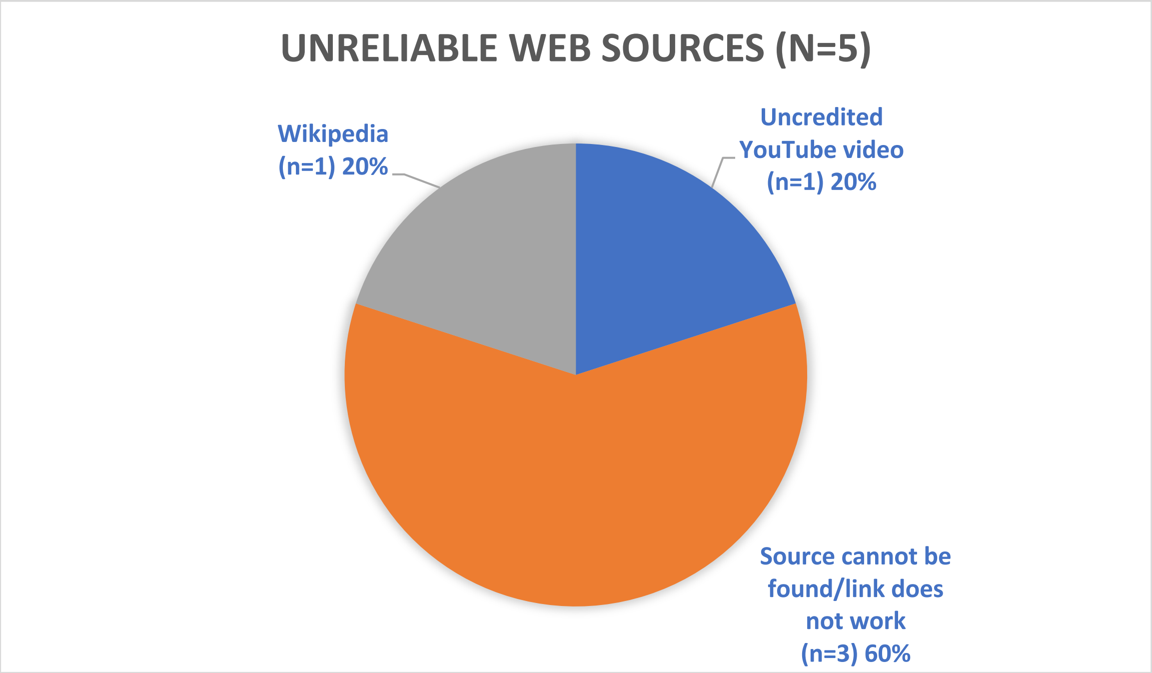


Figure 6-8: Unreliable web sources

6.10 Experiential responses

Experience sharing was a common occurrence identified within the responses (Figure 6-2) but graded as level five (low quality) as they provide no evidence and were based on people's experiences (Table 6-9). A significant number of people felt they could relate to the individuals experience. This led them to share their own and created a community where they did not feel alone coping with their conditions. By sharing their experiences, people offered support to each other as result. This relates to the NPT construct of cognitive participation (relationship work) due to people engaging in discussions with peers and sharing their experiences. This type of information sharing promotes relationship work and helped people legitimise concerns or problems (Table 6-3).

6.10.1 Sharing personal experiences

Often, responders shared their own experiences when they felt able to relate to what the individual discussed. Responders shared their experience of the difficult process undertaken to obtain a diagnosis, of symptoms and conditions suffered, of treatment and medications received, and of relationships. Usually, people reacted well when the responder shared their own experiences, since this made them feel part of a community and less alone. Frequently, individuals wanted to share and compare experiences. This generated suggestions in changes of approach for the fellow peer to use.

> I was going to post something similar. I've been back and forward to the Drs and hospital for months with similar symptoms.

6.10.2 Sharing supportive experiences

Support through experience appeared beneficial, since people demonstrated to the user that they are not alone. The responder has previously experienced something similar, and he/she reassures the individual that there is hope. A key difference exists between sharing personal experiences and sharing supportive experiences, since the former exercises the powerful ability to ensure that individuals understand they are not alone with their illness, preventing condition isolation.

> I’m sorry about what you’re dealing with, I suffer the same things. If you need someone to talk to who’s similar let me know and I’ll talk with you. It’s always nice to know you’re not alone.

6.11 Informational responses

Informational responses provided substantial intelligence not with the aim to diagnose, but with the objective of offering knowledge to answer a question and were commonly distributed within the responses. These included advice around the condition, lifestyle changes, suggestions on medication and more. These relate mostly to the NPT theoretical construct of coherence (sense-making work) as respondents sought to find out more information by asking the user follow-up questions in order to provide more efficient advice. Cognitive participation (relationship work) is another construct related to this theme as the sense-making work begins a discussion process where information is being shared between peers, providing assurance for one another (Table 6-3).

6.11.1 Finding out more information

Finding out more information included responses following requests for more expertise from the individual who posted, while answering their initial questions. These replies were classified as informational, since they provided knowledgeable advice while requesting more facts at the same time. By finding out further information, a sense of interest in the individual's situation was triggered, contributing to the establishment of a relational bond between participants. Usually, after posting a query, the individual expressed gratitude towards the user who responded, who helped finding a satisfactory conclusion to their questions while asking further details about their situation and providing additional informational advice.

> What does the chest pain feel like? I'm not a doctor but does it hurt when you breathe in?

6.11.2 Giving advice

A significant difference exists between providing advice around a condition and providing diagnostic information. This divergence recognises that providing advice does not equate with giving a direct diagnosis to the individual. Therefore, advice was offered in an informational way steering the individual towards services and further resources. Users who responded included information that answered the question directly and made suggestions on what the individuals could do next.

> Stress is a big part of the equation. Relaxing is the cure and one excellent way to do that is exercise. Keep it up!

6.11.3 Advising against internet advice

Some responders felt that individuals should not rely on the internet or searching Google to determine their health condition and should not receive a diagnosis online. Responders suggested this could generate unnecessary stress and worry because of the overwhelming amount of retrievable information, navigation difficulties and the problem of identifying reliable sources. The individuals themselves suggested that this practice could be unreliable and were aware that they should visit a trained HCP instead.

> The internet will only give a broad diagnosis. Be cautious when researching on the web.

6.12 Peer relations

We examined patient's communication which led to relationship building responses. A community is characterised and arises from posting in online health forums. Within these communities, relationships become established as the main purpose is to provide support for individuals in their time of need. It was found that many responses were supportive, but others led to tension and conflict. This relates mostly to the NPT constructs of cognitive participation (relationship work) as this is the peer-to-peer engagement process, as well as reflexive monitoring (appraisal work). The peer-to-peer engagement process leads to peers working together to collectively make a decision (Table 6-3).

Usually, supportive responses let the individual know that they are not alone, and they have found support within the community. Consequently, the user posted regular updates and found comfort from like-minded people that replied and related to them. Some supportive responses included similar experiences with a positive outcome, increasing hope for the individual.

> You're not alone anymore! We will show compassion and support anytime you need to talk.

However, peer conflict occasionally occurred when people raised their frustrations with a user's post, or within the responses of the post. Some people became frustrated when they felt the post included obvious signs of anxiety, which the user misunderstood for heart issues. Some people also felt that many younger people were misunderstanding anxiety symptoms with heart issues which became frustrating for them.

Some peers responded negatively towards 'bible preachers' and felt they should not be allowed further forum participation. Others disagreed occasionally with responders, leading to further conflict regarding the user's situation.

> Your worrying made me mad, absolute nonsense if you ignore the doctor's advice.

6.13 Relationships with the healthcare professional

Peers frequently reported on their relationships and thoughts towards their HCPs. Some experienced disappointment after HCP consultations and decided to use online health forums to seek a second opinion. Others were pleased with their HCPs, trusting them and believing them to be experts. This relates mostly to the NPT constructs of cognitive participation (relationship work) as this relationship work extends beyond the peer engagement process and determines the link between the relationship with online health forums and HCPs. Reflexive monitoring (appraisal work) is also related to this theme because the interactions help inform the decision-making process, for example - whether the user will visit the HCP based upon the information they received online (Table 6-3).

6.13.1 Positive experiences with HCPs

People reported positive experiences with their HCPs after consultations. Some felt that they could trust the HCPs, since they were experts in their field. In addition, people were reassured when cardiologists had previously received good reviews, making them feel more comfortable and trusting. Moreover, it was discovered that some individuals felt nurses possessed a great ability to speak to them in a very relatable manner. This simplified their consultation experience enabling better understanding of the whole process.

> Above all, trust your doctor, he is the expert.
>
> Cardiac wards usually have an educational nurse... they are good because you get the terms spoken with you and not at you with terminology that goes over our heads.

6.13.2 Distrust with HCPs

Some responses expressed people's frustrations with their HCPs. Often, people felt dismissed and not listened to when visiting their HCP. Usually, this perception led them to online health forums for finding another HCP and seeking second opinions. Time issues were commonly reported: individuals said they often felt rushed during their consultations. Interestingly, there was the belief that some HCPs were only interested in receiving the fee after the appointment, hence recommending further visits for other tests to gain more money. Others felt their health issues were not taken seriously enough and lost trust with their HCPs knowledge.

> They have this obnoxious habit of not listening to patients, when we tell them things, they think they know better.

6.14 Conclusion

This chapter presented the findings of the heart failure online health forum research. Thematic analysis (Braun & Clarke, 2012) was employed to analyse the data and the data conceptualised through the NPT lens (May & Finch, 2009) to help understand the types of information sought and provided. Responses were analysed for quality of evidence against the NICE and SIGN guidelines. The findings concluded that after a heart failure diagnosis, some individuals felt they were not given sufficient information regarding how this would influence their lives. Some felt that their HCPs were vague and, when diagnosed, they sensed that some HCPs were not forthcoming with information about the severity of their condition. Findings from phase three (the interview study) of the research are presented in the following chapter.

Chapter 7 - Findings: Perceptions of Online Health Information Seeking and Self-Diagnosis

7.1 Introduction

This research started with a systematic review of the literature looking at the effects of patient online self-diagnosis on the patient-HCP relationship. Based on the results of the review and the findings from previous studies, a qualitative study of the perceptions of the public and HCPs on patient use of the internet was then undertaken, using one-to-one, semi-structured online interviews.

The aim was to identify and explore the way the public and HCPs interpreted the use of the internet for procuring health information. More specifically, to understand motivations and reasons for using the internet; decision-making processes; the role of the internet in diagnosing; treating and finding further information on heart issues; gaining an understanding of how the public feel about communicating this behaviour and the information retrieved with their HCP; the perceptions of HCPs discussing patients use of the internet for health information and if they feel it has changed their relationship with patients.

As this study was undertaken during the COVID-19 pandemic, the online retrieval of health information concerning COVID-19 and the impact of the pandemic on their relationship with healthcare systems, professionals and information sources was also explored.

This chapter is organised into two main sections. The first section presents the findings on the public's interpretation of the phenomenon and the second section will discuss the findings of the HCP's perceptions.

7.1.2 Research questions

The following research question are addressed in this chapter:

RQ1. *How does online health information seeking affect the patient-HCP relationship and medical authority?*

RQ2. *How do HCPs perceive patients use of online health information and its effect on the patient-HCP relationship?*

RQ3. *How do public/patients perceive the use of online health information and its effect on the patient-HCP relationship?*

RQ4. *How does online health information seeking shape people's decision-making?*

RQ9. *How has the availability of online health information influenced the patient-HCP relationship?*

RQ10. *What are the perceptions of online health information surrounding COVID-19 and the impact of such information among healthcare services?*

7.2 Methods

A thematic analysis, informed by Braun and Clarke (2012), was undertaken to establish a list of themes and sub-themes. Each item of extracted data was coded independently and then mapped onto the constructs of the NPT framework to aid conceptualisation of the data (Table 7-1; Table 7-2).

Table 7-1: Normalization Process Theory coding frame for public perceptions

Coherence (Sense-Making Work)	**Cognitive Participation (Relationship Work)**	**Collective Action (Enacting Work)**	**Reflexive Monitoring (Appraisal Work)**
Differentiation	**Initiation**	**Interactional workability**	**Systemization**
The initial search processes. Navigating sources to gain an understanding of the symptoms and differentiating diagnoses.	Implementing the decision-making process. Deciding to engage in online health forums, book a healthcare appointment, or satisfied with the	Further action of the decision-making process. What to do with the information received. Communicating complex health issues	Determining the benefits and risks of online self-diagnosis and health information seeking on online health forums. Determining HCP's reactions to

	information gained from the initial search.	online with peers. Self-management.	presenting internet information. Collecting an understanding COVID online health information.
Communal specification	**Enrolment**	**Relational integration**	**Communal appraisal**
Developing knowledge and understanding of heart symptoms. Participating in further search strategies such as online health forums.	Information sharing and communicating with HCP's and/or online health forums.	Developing trust and building accountability. Understanding resources and developing a relationship with HCP's. Sharing advice and issues and gaining support.	Understanding the effectiveness of the decision-making process. Evaluating COVID online health information. Evaluating trust within the relationship.
Individual specification	**Legitimation**	**Skillset workability**	**Individual appraisal**
Interpreting internet health information. A process of elimination of possible conditions. Developing further knowledge and understanding of symptoms and navigating sources.	Determining the differences between the internet diagnosis and HCP's diagnosis. Reflecting if they felt taken seriously.	The prepared patient. What to do with the information gained.	Working to understand what works best for the individual. Evaluating and reflecting upon the process.
Internalization	**Activation**	**Contextual integration**	**Reconfiguration**
The process of decision-making.	Communicating effectively with HCP's and/or online health forums.	Making the decision of what types of resources are of preference to the user.	Understanding how effective online health information is for diagnosing and seeking health information for heart failure. Understanding the patient-HCP relationship process

			and sharing internet health information.

Table 7-2: Normalization Process Theory coding frame HCP perceptions

Coherence (Sense-Making Work)	**Cognitive Participation (Relationship Work)**	**Collective Action (Enacting Work)**	**Reflexive Monitoring (Appraisal Work)**
Differentiation	**Initiation**	**Interactional workability**	**Systemization**
The understanding of patients using the internet for health information and self-diagnosis and patients presenting with internet findings.	The HCP response to patient's presenting online health information.	Communicating complex health issues online with peers. Self-management.	Determining the benefits and risks of online self-diagnosis and health information seeking on online health forums. Determining HCP's reactions and perceptions to patients presenting internet information. Perceptions of COVID online health information.
Communal specification	**Enrolment**	**Relational integration**	**Communal appraisal**
Engaging with patient's online findings and providing education and understanding around them. Understanding knowledge deficits and health literacy to provide appropriate information and education.	Communicative approaches and actively listening to the patient's concerns and research findings. Engaging in shared decision making.	Developing trust and building accountability. Understanding resources people may be accessing and developing the relationship. Providing support while adhering to	Understanding the effectiveness of a professional partnership and shared decision-making process. Evaluating COVID online health information. Evaluating building trust within the relationship.

Individual specification	**Legitimation**	**Skillset workability**	**Individual appraisal**
Interpreting conflicts of information between the self-diagnosis and HCP diagnosis. Providing further knowledge and education that is person centred towards the individual based upon judgement of health literacy and knowledge deficits.	Determining the differences between the internet diagnosis and HCP's diagnosis. Reflecting if they felt taken seriously.	Signposting patients to other HCP's or recommended online resources.	Working to understand what works best for the individual. Potentially based upon sociodemographic and health literacy. HCP evaluation and reflection upon the process.
Internalization	**Activation**	**Contextual integration**	**Reconfiguration**
The behavioural approach and communication methods towards internet-informed patients. Engaging and understanding.	Working together in a professional partnership and shared decision-making process in a way that is tailored towards the individuals needs and preferences.	Providing support for patients while adhering to their own medical model of diagnosis and guidelines. The work of integrating both patient beliefs with the HCP medical model to reach a conclusion.	Understanding how effective online health information is for diagnosing and seeking health information for heart failure and issues. Understanding the impact on the patient-HCP relationship process and the role of HCP reactions to internet informed patients.

A total of 31 participants were included in this study. All participants engaged in online interviews using Zoom. The sample consisted of public participants (n=16) and HCP participants (n=15).

The public sample consisted of 12 females and 4 males (Table 7-3). Thirteen of the participants were of employed status, one was unemployed and two were retired. All participants were below the age of 70 (Figure 7-1). All public participants declared experiences of online self-diagnosis or health information seeking.

The HCP sample consisted of 12 females and 3 males (Table 7-3). Eight of the participants were nurses (ward nurses; cardiology specialist nurses; emergency nurse practitioner; deputy charge nurse). Four were doctors (GP's and junior doctor) Two were physiotherapists (cardiology specialist physiotherapist), and one cardiac physiologist. All participants were below the age of 70 (Figure 7-1). All HCP participants proclaimed experience of patients using the internet for self-diagnosis and health information seeking.

Table 7-3:Sample demographics

	Public participants (n=16)		**HCP participants (n=15)**	
Sex	Male	Female	Male	Female
	4	12	3	12
Employment status	Employed (n=13) Unemployed (n=1) Retired (n=2)		Employed (n=15)	

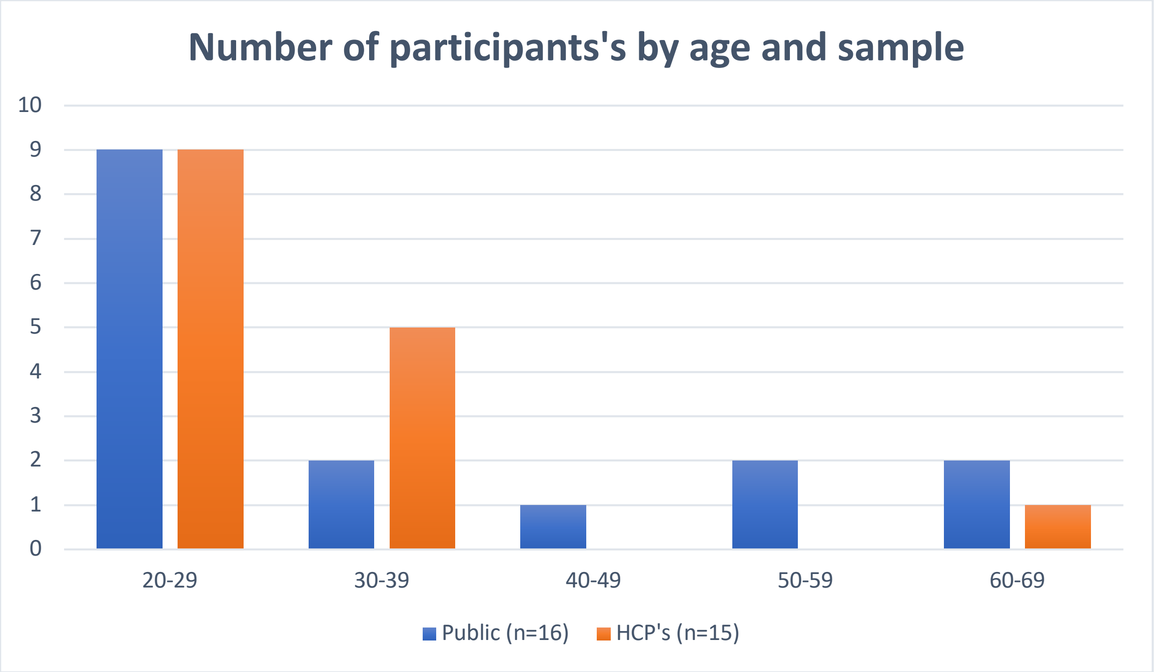


Figure 7-1: Number of participants by age and subsample

7.3 Public perceptions

Interviews with members of the public led to identification of five major themes: 1) reasons and motivations for using the internet; 2) understanding the potential issues using the internet; 3) online health forums and social media as an information source; 4) the impact of online health information seeking and self-diagnosis on relationship with HCPs; and 5) the information impact of COVID-19. The major themes and additional sub-themes identified from the analysis are summarised in Table 7-4: Themes and sub-themes. Themes were identified and data were thematically analysed and conceptualised through an NPT conceptual lens. The participants were identified by pseudonym (e.g., participant 1 – P1).

Table 7-4: Themes and sub-themes

Themes	**Sub-themes**
Reasons and motivations for using the internet	• Holistic health • The active/prepared patient • Healthcare systems

	• Eliminating fears and addressing emotions • Seeking reassurance • Accessibility • Seeking as a carer or relative and considering family history • Interpretation, processing and anonymity
Understanding the potential risks using the internet	• Fear confirmation • Overwhelming and unreliable information • Impact on mental health
Online health forums and social media as an information source	• Support for people with heart conditions • Sharing experiences • Networking • Negativity • Trustworthiness and validity
The impact of online health information seeking and self-diagnosis on relationship with HCP's	• Signposting • Shared decision-making and adopting a partnership approach • HCP's behaviour, characteristics and reactions to internet-informed patients • Trust • Time constraints
The information impact of COVID-19	• Access to services • Living with cardiac conditions during COVID-19 • Dissemination of COVID-related online health information

7.3.1 Reasons and motivations for using the internet

The most prominent theme from the analysis of the interview data of public perceptions, was the public's reasons and motivations for using the internet for health information, which captured the overall perceptions of online self-diagnosis and health information seeking. Several subthemes were identified through thematic analysis: holistic health; the active/prepared patient; healthcare systems; eliminating fears and addressing emotions; seeking reassurance; accessibility; searching as a carer or relative and considering family history; and interpretation, processing and anonymity.

This theme arose from the prompts "what are your experiences with online self-diagnosis and using the internet for health information?" and "what was your motivation for using the internet?".

These relate mostly to the NPT theoretical constructs of coherence (sense-making work) as people were drawn to the internet for health information to help them better make sense of and understand their symptoms and appropriate management. Collective action (enacting work) also relates to this theme as it is the process of gathering information to make an informed decision.

Each sub-theme will be explored with exemplars provided to illustrate the meaning of each sub-theme and the interpretative process to elicit the sub-themes.

7.3.1.1 Holistic health

Searching for holistic healthcare (physical, mental, social and spiritual needs), was an important reason why people used the internet for healthcare purposes. Several advantages that helped enable holistic health searching, included the benefit of the internet providing multiple sources at one time, allowing unlimited information gathering. People reported only receiving physical health information from their HCP and felt they could benefit from mental, social and spiritual support, and had wished this was discussed with them in their appointments, or at the very least acknowledged. As a result of the lack of holistic information in health appointments, people commonly sought this information from online.

Participants reported the importance of not only seeing an illness as physical. They felt it would have been helpful if they were warned or more prepared for how physical symptoms can have a major impact on their mental health, social life and spiritual needs. Participants felt if they were better educated on the holistic elements of their condition in addition to diagnosis and medications, it would promote better management and control of their condition.

> It's not just the thing that you're dealing with, it could be whatever condition it is. It's all the other things that impacts on your ability to work, your ability to care, your finances, your planning for the future, everything, it affects everything. **P11**

Participants stated that HCPs, in particular GPs, restricted themselves to diagnostic feedback. For example, it was explained that although HCPs continually monitor your bloods or tests, there are limited opportunities to report the impact the diagnosis can have on other areas of life. People felt it would be beneficial if more primary care sources were available to discuss these types of concerns.

> You don't get that time with a GP. The GP just says, this is the answer; you have a problem, this is the solution. And they don't look at all the side effects and the bigger picture, and there's not really that much of a feedback loop. **P13**

7.3.1.2 The active and prepared patient

The active patient was described as someone who wants to become more informed about their health and who aims to work in a professional partnership with their HCP. People with heart conditions reported regularly using the internet to source newly published research, new surgical methods or any updates about their conditions, which helped them communicate better with their HCP. Some participants used Twitter to find the latest research that HCPs shared so they can build evidence-based knowledge.

> I do spend quite a lot of time doing online research about my conditions and related conditions. **P4**
>
> What I also thought when I started searching online information is that it would be just, like, some back-up knowledge when I am talking to a doctor. **P4**

The term ‘ownership’ was frequently mentioned by participants as they felt that being involved in their healthcare allowed them to take ownership and responsibility for their health. It allowed them to maintain a sense of control in what they felt was otherwise an uncontrollable situation.

> I think that internet health information has allowed me to take ownership of my own health, whether that’s with or without the health professional’s approval. And for good or for bad, I’ll make my own decisions; but it really puts the power back into your hands. It’s that self-efficacy it all goes back to. It empowers you to try and make informed decisions or rounded decisions and look at other more holistic solutions for a social model of health. **P15**

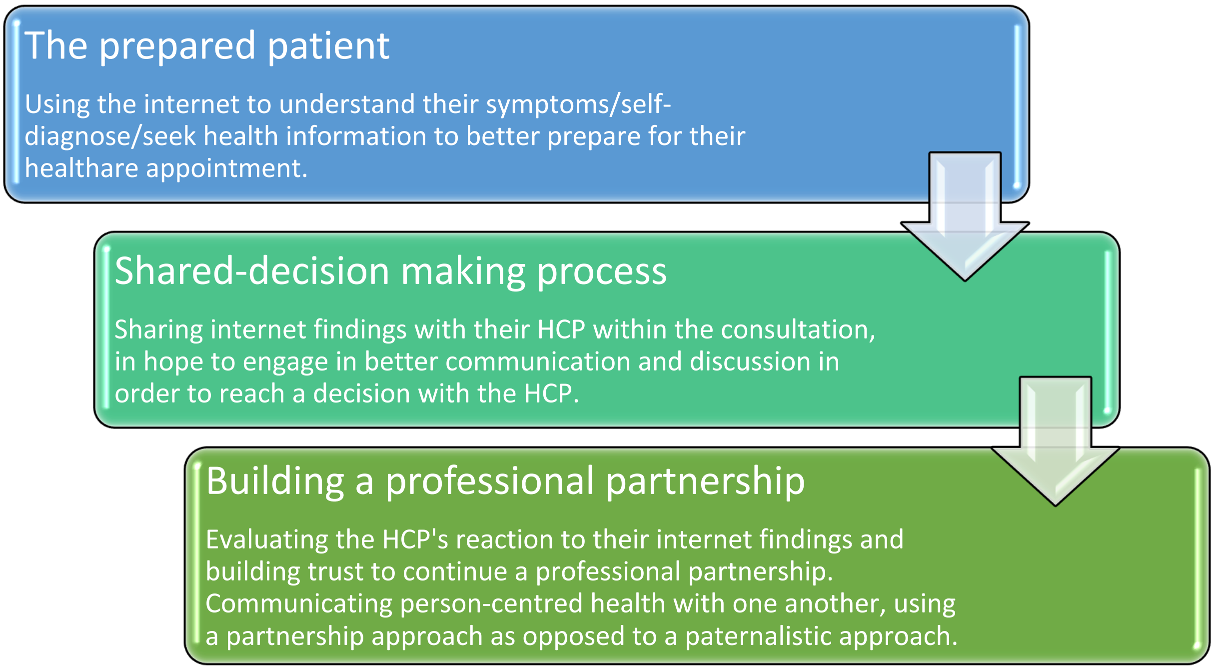
The prepared patient included individuals who gather evidence before and/or after an appointment with their HCP. People sought information to gain knowledge before the appointment, to gather a list of questions, to communicate more effectively with their HCP, or seek further clarity after an appointment. Participants commonly reported searching after the HCP appointment to further understand the information they had gained from the HCP, to help inform their next steps or to find others who may have had similar experiences. Usually, if a follow-up appointment was arranged for a later date, people would resort to online health information to aid them until they are able to seek further medical advice.

> It definitely helps that you have done your research. I don’t know whether it’s peace of mind that you’ve done your research before you go into a doctor so that you know that you’re not feeling like, stupid going into a doctor over something that’s really not anything to be worried over. **P5**

People tended to forget the questions they wanted to ask when they were in the consultation. However, they felt if they did research before-hand, they had a clearer idea of the questions and that they were no longer spontaneous questions, but ones they had pre-existing knowledge on, making it more difficult to forget.

> I actually take a notepad with me. And actually…last time I saw him I had 24 questions written down. **P10**

The prepared patient, shared decision-making, and building a professional partnership formed a pattern of shared perceptions among the participants as presented in Figure 7-2.



The prepared patient

Using the internet to understand their symptoms/self-diagnose/seek health information to better prepare for their healthare appointment.

Shared-decision making process

Sharing internet findings with their HCP within the consultation, in hope to engage in better communication and discussion in order to reach a decision with the HCP.

Building a professional partnership

Evaluating the HCP's reaction to their internet findings and building trust to continue a professional partnership. Communicating person-centred health with one another, using a partnership approach as opposed to a paternalistic approach.

Figure 7-2 The prepared patient model

7.3.1.3 Healthcare systems

Many participants reported using the internet as a result of their healthcare systems (e.g., not able to make an appointment or unable to attain health insurance).

Participants who used the NHS, disclosed that they were generally satisfied with the healthcare system. However, also reported experiences of considerable waiting times to get a referral to another service or to have a follow-up appointment, which may account for the increased use of the internet after a healthcare appointment.

American participants discussed the American healthcare system, which seemed to have more complexities as healthcare services came at a cost. Participants reported that planning to visit the HCP was not a straightforward process as they had to consider their financial status and health insurance policies.

Due to the financial aspect, people felt more wary when visiting a HCP. Some felt suspicious of the HCP wanting to gain financial benefit from their appointment and did not feel they were receiving person-centred care as a result. Participants also reported trying to avoid going to the HCP for what they felt were smaller issues and attempted to self-manage them by using online health information, to avoid paying to use a healthcare service.

> Especially in America where it's hundreds of dollars at a time to see a doctor, they frankly feel like it's a waste of time for you to go and see a doctor for anything that's not severe. So, just getting answers online is quick, easy and sometimes it's the only real logical way to get responses besides trying to ignore them. **P10**

American participants reported that when they are job-seeking, they are not only looking for career benefits but also the health insurance offered. Furthermore, one participant raised the point that even when health insurance is in place, there is still a cost to pay for an appointment upfront until the money is reimbursed.

> It's a lot of money to see a doctor here. Luckily in my last insurances, my first job, I didn't have to pay. My insurance now is $400 for a general health appointment. I think if it's out of hours it's $800. **P10**

The financial cost of healthcare significantly influenced online health information seeking behaviour. One participant explained they would always attend appointments prepared,

> Every opportunity I've had with a general doctor, I've come with a whole list of questions because I don't want to have to see them four or five times. So yeah, I'd come in with a large list of questions and then they'll answer those. **P10**

Online health information and self-diagnosis was a primary healthcare source for all American participants in this study and was acknowledged to be a source that guided their healthcare decision-making.

> The internet is so easily accessible. It has so much information there. It's free. Like why would you not? Especially living in the States, it just seems to be, there is a whole thing going to a doctor because you've not got health…well, I luckily do have health insurance but only select hospitals and select doctors are under your health insurance… When I do go to a doctor, I have to pay out of my own pocket and then get reimbursed by my company which for a ten-minute consultation was like $650 so… can you imagine if something seriously was wrong with you then I just wouldn't

> have that money to even pay. So, I always use the internet for health information, it's the first thing I do. **P7**

7.3.1.4 Eliminating fears and addressing negative emotions

Participants reported using the internet to address negative emotions and attempt to eliminate fears. Negative emotions that drove participants towards online health information included feeling fearful, paranoia, confusion and feeling as if they are in the unknown, as one participant explains,

> I think the Internet is really easy for you to confirm your fears. Like, oh okay, it must be this because I have all of these symptoms, so, it's got to be that. I think a lot of the time it's just the fear of not knowing makes you kind of spiral out of control on some of these things. **P9**

Furthermore, people reported their use of the internet was also due to the suspicion of being misdiagnosed or when they perceived the real diagnosis to be different from the HCP's diagnosis.

> For my own piece of mind and for my own sanity, I was self-diagnosing and looking online for answers. I just wanted to explore every area and make sure there was nothing missed. So, at that point, that was probably coming from a lack of trust in what was she was thinking in her decision-making. **P14**

7.3.1.5 Seeking reassurance

Reassurance was a reoccurring theme used to describe why people used the internet for health information and self-diagnosis which came from the prompt "what was your motivation for using the internet?". One participant described the internet as a "helping hand" tool,

> I don't see it as a final destination but more of a helping hand, so I don't have to always go to the doctor and waste their time. **P16**

Experiencing symptoms or conditions can feel isolating but when people searched online, they realised that their condition was experienced by many, which they found comforting.

Reassurance was commonly linked with feeling “not alone”. The internet was viewed as a community of peers and when you make the search, you suddenly become “one of many”.

> I think the positive is probably that it’s kind of nice when you feel that there is something wrong and you can look it up and there are other people that are maybe dealing with something similar. It kind of makes you feel that maybe you’re not alone. **P9**

7.3.1.6 Accessibility

It was widely acknowledged that one of the main benefits of using the internet for health information was its ease of access. People used the internet because they could access it at any given time and review the information frequently. They identified the internet to be a reliable tool in terms of frequent access to a vast amount of information.

> The internet was available when I could fit it in between my caring responsibilities and my work responsibilities. And the good thing about online information and advice, although you can’t always trust what you read on the internet, it’s available 24 hours a day, seven days a week, which is really accessible to people like myself who are quite busy. **P13**

Additionally, people diagnosed with long-term conditions (e.g., heart failure), explained that when they experienced days of feeling fatigued or unwell, they were able to access resources from home, which helped them feel more at ease to have this option. The portability of online information was a key benefit,

> I think online resources are good because you can just sort of…nowadays you can access it anywhere from anything. Say you’ve got a spare five minutes waiting for something or for a meeting or something, you can quickly have a read of it, without having to carry a pamphlet around. **P5**

Another point raised was the benefit of being able to access online health information from abroad. Language barriers were a concern to people when they were abroad, and the internet helped them translate medical advice and source information at their convenience.

> Mainly because of the language barrier and we're going to have huge conversations with Swedish doctors, I used the internet to help translate. **P16**

7.3.1.7 Searching as a carer or relative

Participants reported searching online because of having a family history of cardiac problems. They felt it was important for them to know the signs and symptoms to look out for, although this sometimes resulted in increased anxiety.

> My dad died of a heart condition, and we didn't know about it. So if I ever feel anything slightly off, like my heart is beating too fast or, like, my blood pressure is too high, I look things up like that. **P12**

Participants that had a family history of cardiac issues, appeared to acquire more knowledge on heart failure and conditions. One participant explained searching to understand more about heart conditions,

> I wanted to figure out, like, why my dad passed away. I guess, because he didn't know that he had a heart condition, none of us knew, so it was really sudden. So, I was just looking up, like, what causes that and how to prevent it and I'm still kind of, I don't know, like, it's still like a fear that I could go the same way. **P12**

One participant who was a carer, also reported using the internet as an information tool,

> I was a carer, my son had an acquired brain injury, so I was a carer for him, and also for elderly parents. One had prostate cancer and the other had a heart condition. So, I was the middle generation that was caring for everyone, working full-time and under a lot of pressure at work. So, I probably neglected my own health because I was too busy dealing with everyone else's, if that makes sense. The internet was my guide on what to do. **P13**

7.3.1.8 Interpretation, processing and anonymity

People often used the internet for interpretation purposes. This was especially purposeful to public participants when they did not understand information received from their HCP and felt more comfortable spending time self-researching without the fear of judgement, instead of asking the HCP more questions. Having time to process information was a limitation in consultations described by participants,

> I mean, you only take in so much information at an appointment. I feel, when you go, they bombard you with all this information. You only take, like, out of the ten points they give you, you only probably remember about three. And it would be good to have a source of information to look back at and just be, like, oh, okay, yeah, I understand now, to just have more time to process it. **P6**

Some participants appreciated the anonymity of the internet as it allowed them to do more honest searching, especially when they may find it more difficult to discuss in face-to-face appointments.

> A lot of the searches that everyone does is very personal. So, the anonymity that's given by the internet also makes you say more honest things. Sometimes I don't really feel comfortable talking to anyone let alone my parents about some of the issues or concerns that I'm having at the given time. So yeah, it's a tool that does a lot of pre-screening, but when things get serious it's important to go to a professional. **P10**

> I didn't dare to ask my doctors and so I thought okay, I can just research it and be anonymous. **P4**

Several participants reported that they used the internet to understand what their diagnosis was and interpret the meaning of their medical letters, test referrals and test results. For example, one participant explained the confusion in differentiating a heart attack and cardiac arrest,

> I came out of the hospital not really having a clue and for example, when I first telephoned my GP to make an appointment, I used the word, heart attack. Got corrected because I hadn't had a heart attack, I'd had a cardiac arrest. So, he corrected me, but then I went online on British Heart Foundation and found a nice, little diagram which showed the difference between a heart attack and a cardiac arrest. So, I found it really useful. **P3**

People discussed finding heart terminology daunting, particularly 'heart failure'. Furthermore, many participants did not understand their test results (ECG results – abnormal) or their ejection fraction percentage and found such unexplained terminology to cause them worry, which led to posting results on online health forums.

> At first, I thought that heart failure was a dramatic thing that your heart was failing. **P11**

> There was so many abbreviations and so many terms I didn't understand. I tried to work out which ones potentially were useful for me to know and to see if they would improve some of them. So, one of them was my EF, my ejection fraction. **P3**

7.3.2 Understanding the potential risks of using the internet

The second main theme discusses the potential issues that may arise from using the internet as a health information source. Although all participants reported using the internet for self-diagnosis and health information, most reported being able to see potential issues arising that could be faced with using the internet, addressing them as "internet obstacles". This theme arose from the prompts "what are your experiences with online self-diagnosis and health information seeking?" and "what are your overall perceptions of using the internet for health information?".

Several subthemes were identified through thematic analysis: fear confirmation, overwhelming and unreliable information, and impact on mental health. These relate mostly to the NPT theoretical constructs of coherence (sense-making work) as sense-making work was happening to understand beliefs and perceptions towards online health information. Reflexive monitoring (appraisal work) was also related to this theme as individual appraisal work and reconfiguration has taken place in order to understand how effective online health information seeking was for that individual.

Each sub-theme will be explored and supported with exemplars to illustrate the meaning of each sub-theme and the interpretative process to elicit the sub-themes.

7.3.2.1 Fear confirmation

People reported being drawn to the internet as a result of being concerned about an issue. In some cases, they were already worried before internet searching. This had potential to have an impact on the type of information they would search due to being at an already heightened stress.

> It made me feel quite negatively, but I think I was looking through a lens as well, like through my own lens. Homing in on the worst of things and also homing in on the minority of people who have faced things like permanent heart problems and also, it's taken out of context as well because I didn't care to read properly. **P7**

Participants described having a combination of fear and access to a large amount of information with no filter methods, to be a recognised risk of online health information searching.

> I was so kind of desperate and so scared that I didn't really worry about how I was coming across. In the sense that I was a hypochondriac. I wasn't worried about how I looked; I was just so desperate for an answer. I didn't really hesitate to contact them. **P9**

7.3.2.2 Overwhelming and unreliable information

Participants reported there to be difficulties in filtering information found online. This was especially hard when there was no clear answer to the problem being searched for, which caused some people to feel overwhelmed. In a HCP appointment, there is a time limit however, internet searching can be endless which can lead to people feeling lost in information as reported by one participant,

> I mean, obviously it can be overwhelming, the sheer volume of data. And if you don't have a steer on how to navigate that, you know, you can just drown in the data. **P2**

Misleading information was another reported cause for concern. For example, searching for symptoms such as a headache, could lead to numerous suggestions such as signs of cancer which could be taken out of context. Furthermore, one participant concluded that feeling worried and overwhelmed, can influence the types of information sources being accessed and can lead to unreliable sources of information,

> I think the problem is when you're in that heightened state of stress, you're probably less likely to think rationally and to be able to separate reliable and unreliable information. So yes, I think it could be quite dangerous in that way. **P9**

7.3.2.3 Impact on mental health

Mental health was frequently discussed by participants. However, the internet did not always positively impact their mental health. One participant reported the internet as being the most problematic at the pre-diagnosis stage when they perceived themselves to be in the unknown.

> I think I would be wary now of using the internet. Just because I know the state it put me in at that time. I think I also didn't realise how much stress could affect you physically. And I never really considered that. So, I think that now I would just completely avoid using the internet. **P9**

Some people using the internet for heart conditions also had mental health conditions and needed extra support both physically and mentally. It was further discussed by some participants that they would find it beneficial if cardiac web sources and HCPs provided more mental health support as a side-effect of their heart condition.

> So, if your cardiac consultant is saying okay, this is what's happened to your heart, it's this, it's that, you need to watch out for this and do this and whatever… And by the way, you've just been through a very traumatic experience; there will be mental health impacts on you. This is normal. So rather than the depression and anxiety or stress or being, kind of, separate to the condition, I think more could be done in all platforms to say this is not a bolt-on; this is a part of the condition. So that when you do have an MI at age 39, out of the blue, that nearly kills you, guess what, you're maybe going to need some help. **P2**

Another participant explained the difficulty of not being able to do the activities she was able to do pre-diagnosis and how it can be hard to stay positive in such situations.

> You can't do the things that you used to do. I can't look after my grandchildren the way I would want to because I have all these symptoms. You know I am not able to do what I'd say a normal person should be doing. You know I go out, go swimming, I get a urine infection. If somebody says join a walking group, if I go out walking and its freezing cold, I'll get a chest infection, you know, and I know that. You know, okay, people say

> be positive, but you have to be realistic as well about what you can actually do. **P14**

7.3.3 Online health forums and social media as an information source

Online health forums have become an increasingly popular tool for peer-to-peer healthcare, allowing users to engage in healthcare discussions at any given time. However, the findings reveal mixed opinions about the usage of online health forums and this section explores positive and negative perceptions and potential improvements. Several sub-themes are addressed: support for people with heart conditions, the shared experience, networking, negative perceptions and trustworthiness and validity. This theme arose from the prompts, “what type of sources do you use?” and “have you used online health forums as a resource?”. This relates mostly to the NPT theoretical constructs of cognitive participation (relationship work) as online health forums and social media support groups involve communicating and information sharing with others online. Collective action (enacting work) is also related as this also involves communicating health needs and gathering information online.

Each sub-theme is discussed with exemplars provided to illustrate participants’ interpretations.

7.3.3.1 Support for people with heart conditions

Online health forums and social media support groups appeared to be more favourable to those already diagnosed with a long-term condition such as heart failure. It was supportive and hopeful to some participants to meet other peers and exchange informal information. One participant discussed these groups being helpful after his surgery,

> It was very helpful when I had my surgery, for example. I had my first heart surgery last year, so I was very old for a CHD patient for the first heart surgery. But in that situation, I felt it was very helpful because the others in my CHD group, they knew what surgery looked like. They knew everything around. They knew, okay, you have to go there, you have to do this appointment before, and they knew how the recovery would maybe look like. I thought this was a support situation. **P4**

> I found a group on Facebook and their information has been invaluable since then. All sorts of things, from what to do about my driving licence because I had to give it up for six months. I've found more information online than I have from the doctors. **P3**

7.3.3.2 The shared experience

Some participants found comfort in engaging in online health forums because they felt they were part of a community with people sharing similar experiences. This felt reassuring for them because other people understood their experiences from a personal stance.

> I wanted to know there were other people that felt the same as I did. So, first of all, it was very much from a physical point of view. This has happened to me physiologically. This is my physical body; this has happened. Has this happened to somebody else? But then as the journey proceeded, it became less about the physical but more about the mental. So, it was about knowing and getting that reassurance and that comfort and that, kind of, shared experience that other people were also feeling the way that you were feeling. **P2**

One participant discussed the rarity of her heart condition, and although there are larger numbers of people diagnosed with heart conditions, there is a small pool of people diagnosed with her specific type of condition. Therefore, although she is part of a community with many others with similar experiences, few can share the rarity of her individual type.

> If there were a couple of people with similar problems, similar conditions, that would be awesome. Unfortunately, my CHD is a very rare one and there are not many people who really have this CHD. So, the CHD community is so many people, but there is a very wide range of symptoms and conditions and how people feel. And some people hardly feel any symptoms, they seem normal, and some people are hardly able to live their life. So, this is a very wide range and if there were some people who would be in my little spot in this range, that would be great. **P4**

7.3.3.3 Networking

Networking was noted as a key advantage of online health forums and social media support groups. The opportunity for connection and communication with peers around the world provided hope and unity and led to relationship building.

> I've made some very good friends as a result of those groups and in fact went on to form a, kind of, a patient group as a result of one of them for a very short space of time. So, having that ongoing relationship and then friendship with those people has been just… You can't imagine your life without them. **P2**

Networking with other peers allowed some participants to feel more connected to others. They explained that it was beneficial to meet others with the lived experience because although HCP's had the acquired knowledge and skills to provide advice, they often did not have the experience of what it feels like to have the condition. Therefore, people found comfort in online health forums, as they found relatability to others.

> Well, things like talking to people that have gone through these things. People seem to understand more than others … The doctors knew how to treat me when I was down, but they don't necessarily know how I can recover fully and get back to a near-normal life or a normal life as it will be in the future. **P3**

> I think obviously when things are that little bit rare, you do feel, you know, an extra bit isolated. So, it's good to make these connections. **P2**

7.3.3.4 Negative perceptions

It must be understood that there is an opportunity for conflict to arise on information sources such as online health forums. One participant discussed possibilities of why conflict may arise on online health forums,

> You've got to bear in mind, a lot of these people are dealing with a lot of serious health problems, and it plays with your head. You think it doesn't, but it does. You're dealing with a lot of serious, you know. You're ill or you're tired all the time, I mean I'm tired all the time. You feel kind of low grade unwell a lot of the time, do you know what I mean? **P14**

Some people used online health forums and social media groups for observation purposes as opposed to participating as they felt it could be tiring to become an active participant.

> And sometimes forums and Facebook groups and all that, sometimes you can become totally immersed in them, but sometimes you've got to step back from that as well because it can be quite negative. **P14**

Several participants shared the perception that users of online health forums tended to post more negative healthcare experiences as opposed to positive ones, which led them to feel more cautious about using them.

> I've read them, but I feel like a lot of times people are venting. I've read a whole bunch, and it's just horror story after horror story. I did that when I was in high school once, and I was like never again. Not only did it get me really scared and stuff, but I just felt like it was kind of misguided information. **P10**

Several participants raised the point that although people may be experiencing the same conditions and symptoms, it does not mean each individual will react the same way. Although the experiences are described similarly, they may be felt differently.

> My view is there would be too many risks with this because it's quite subjective and we're all individuals with different DNA and different health history and different lifestyles and if someone was to take their advice from a non-professional on having similar symptoms, I would say that's too much of a risk and can take someone down the totally wrong path. So, I have seen them, but I've not participated in them, and I wouldn't go there. **P11**

7.3.3.5 Trustworthiness and validity

Participants reported mixed perceptions regarding the trustworthiness and validity of online health forums and social media support groups. Some participants reported trust in such sources as they found it difficult to believe why people would take time to share their story if they were not being genuine.

> I feel like in the realm of health online, I don't feel like it's very common for people to post for no reason. I don't feel like it's comfortable to make

> stuff up or anything. Because why? Why would you do that? Why else would you be on a forum if you're not struggling yourself? I think it's almost one of the better sources. Because people have gone to the effort trying to find other people that have those things. And they feel genuine. **P16**

On the contrary, some participants found it difficult to source reliable and high-quality information on forums as most of the information shared from users, did not include evidence or citations to references that supports the validity of the user's posted information.

> As far as getting information in a forum, without knowing the people who are behind the keyboard or the camera – that isn't how I like getting my information. The information integrity is really low when it comes to things like that. There are no citations for anything. It's just some people trying to diagnose people. I don't look at forums as the primary source of diagnosing myself if that makes sense. **P10**

Some participants felt more comfortable using web sources that are accredited by a health board or organisation instead of using online health forums, as one participant explained,

> I'm quite careful about what sites I use. If it's the NHS site, then yes, I trust that, but there are lots of forums and things I wouldn't necessarily trust. I would be cautious…more cautious about them and not overusing them also. **P1**

One frequently reported reason for lack of trust with online health forums was the possibility of being suggested a diagnosis by an individual with whom there has been no former connection. As internet allows individuals to pose anonymously, they could exaggerate or lie about the credibility and the validity of their statements and may not be genuine. This decreased trust among some participants.

> I might read it, but I would always take it with a pinch of salt because it could be, I don't know, well, anyone can post on them, they're not healthcare professionals. **P1**

Furthermore, participants felt sceptical about the accuracy of information provided when users did not have information on the posting individual's medical history and background.

Therefore, they did not feel online peers were qualified to diagnose or provide tailored medical advice.

> If they don't fully understand your history of the whole thing then … if you just speak to that person briefly, then how do they really understand what it is? **P5**

Participants reported that they would be more trusting to participate in online health forums and social media support groups if they were moderated or had HCPs involved in the discussions, moderating the integrity of the information being discussed. If this was the case, some participants who were sceptical said they would be more open to becoming involved.

> If there was a way that someone would make me feel like the issues, I just brought up could be wealthily addressed like for example, if there was a team of doctors or residents or nurses, and then there was a way for them to respond in a way that they would make sure that the information was right, then sure. **P10**

Additionally, participants reported they would find it beneficial if there were more online HCPs. Whether they are monitoring online health forums, answering videoed 'frequently asked questions' where you can submit questions to them, or social media HCP 'influencers' that share healthcare knowledge to a public audience. A healthcare video-conferencing platform was another valuable option suggested. These suggestions arose from the prompt, "what would make you feel more comfortable using sources such as online health forums?".

> I would like to see professionals on the internet. Because sometimes you can find information on a site from a university or something like that, but a lot of information is from non-professionals, and I would be even more secure if I found more information from professionals on the internet. **P4**

7.3.4 The impact of online health searching and self-diagnosis on the relationship with HCPs

As internet usage increases, it is important to understand how this is impacting the patient-HCP relationship. This theme includes several sub-themes: signposting sources; shared decision-making and adopting a partnership approach; HCP behaviour, characteristics and reactions to internet-informed patients; trust; and time constraints. This theme arose from the prompts, “do you share your internet findings with your HCP?” and “do you feel accessing online health information has impacted your relationship with your HCP?”. These relate to the NPT theoretical constructs of cognitive participation (relationship work) as this involves information sharing with HCPs and communicating health needs. Reflexive monitoring (appraisal work) is also related as this involves the reflection and appraisal of how behaviours such as online health information seeking, impact their relationships with HCPs. Each sub-theme will be discussed with exemplars provided to illustrate how participants interpreted each sub-theme.

7.3.4.1 Signposting sources

Participants appreciated when HCPs signposted and guided them to reliable health information online. It reassured people that they were looking at reliable information tailored towards their needs. Those who had not experienced being signposted by their HCPs, expressed that they would like to be,

> I guess maybe the clinicians could be signposting, you know. Even if it’s during appointments or whatever. To say follow this or this is the website for that, use only these sources. So maybe a bit of signposting would be helpful. **P2**

HCPs sharing research papers was said to be propitious, as participants reported that finding research articles was more difficult for them to navigate.

> I was fortunate enough to have some cardiologists who would actually signpost papers to me. So that was a help. So, I knew they were absolutely credible sources. Identifying that when you are trying to research by yourself … There are just so many papers out there, and you don’t know what journal is producing what. And you do have to be careful. **P3**

However, a point raised several times by participants was not feeling prepared for the impact of their diagnosis. They addressed the issue of time in a HCP consultation but believed that it would help if they at least had recommendations from HCP’s of sources to use that discusses the physical health condition and issues around the diagnosis such as mental health.

> At the start of this journey, I thought the physicians are excellent. I have to say they were excellent at giving me all the information I needed. So, when I left hospital, I was given all the heart packs, and I was told I was going to get cardiac rehabilitation and I would be referred here. So, there was a lot of information put out there. But what was not made clear to me, and probably if it had been it would have saved a lot of heartache, is that this is not just a physical condition. **P6**

Another method of signposting was guiding individuals to the services of another HCP. People often reported that they were given results but offered no explanation. This was usually from the primary care practitioner who referred them to a cardiologist to discuss the results. This worried participants as they had to wait to know what was wrong with them, which led them to the internet, especially in scenarios when they had to wait a considerable time for their appointment with the cardiologist.

> If I speak to the GP about cardiac issues, he just tells me that he's not a cardiologist and that I should speak to my cardiologist. **P3**

Out of sixteen participants, twelve said they had never been signposted to online sources or received recommendations for accessing health information after the appointment. Four said they had and felt reassured as the source was recommended by their HCP. All participants said they would find being signposted by HCPs to online health information highly beneficial and would have more trust in the sources they are using.

> If say, they could give me a link to a website which documents that condition and how it can affect people, then it would have just been an easier way of doing it, rather than having to look for yourself. Then if they were able to do that, then you would sort of … basically you'd trust them. So, you would trust the information from whatever website they gave you. Rather than reading something online and thinking, I don't know how good this source is. That would be quite a good thing, I think. **P5**

Some participants reported receiving leaflets instead of online resources. While this was received well as a short-term source, participants mentioned that it became repetitive and was not flexible information that could answer follow-up questions, or they could frequently access. Additionally, they had the possibility to lose or misplace leaflets and pamphlets which did not happen when the information was online.

> I was given a leaflet which was great, but for me personally, online sources would be preferred because I am busy, and it would mean I would be able to look at the information at any time. And it would help knowing my doctor or nurse had approved and recommended the information I was looking at. **P12**

7.3.4.2 Shared decision-making and adopting a partnership approach

The ability to contribute towards healthcare decision-making was important to participants and one of the reasons they searched online for health information. Some participants believed there was a paternalistic manner adopted by some HCPs; however, most hoped for a partnership approach. One participant reported feeling more included when the HCP would begin the consultation by asking what they thought was wrong and if they had done any previous reading,

> The doctor then asked me, what do you think it might be? So, I think it's nice to, kind of, feel that you have…well, not a say because ultimately it is your health. But it is nice to be part of that decision-making process, I'd say. **P1**

Another participant reported experiences of the paternalistic approach while hoping for a partnership approach,

> It's like sometimes the health professional wants to take the power out of your hands to make informed decisions about your own body and your own health because they are the professional. Whereas it should be a partnership approach between the patient and the consultant or the GP. **P13**

The participant went on to explain how she felt the adoption of the partnership approach could improve the relationship,

> I have to say it's very easy to sit as a layperson and read things on the internet and think you know better than the doctor, and I'm not trying to say that I do. But what I'm saying is it needs to make sense when they're having a dialogue with you. They have to be willing and open to explain the decisions they're making and what impact that is, and listen and hear when you say no, that won't work for me, and these are the reasons why.

> It has to be a two-way dialogue. And a lot of the time, it's not a two-way dialogue; it's a one-way diatribe that they tell you. They're taking away that efficacy again; it's all about that efficacy that you are in charge of your own body and your own life.
>
> A decision-making process, I think it's key that the doctor understands the holistic, the person in front of them. It's the social work thing: it's not just a person with a difficulty or a problem or a condition; it's that person and what that means to that person. It's very personalised medicine and a personalised approach. And although the policy says that personalisation is key and that realistic medicine where people are listened to, have good conversations. A good conversation model where you actually listen to the patient, that doesn't necessarily happen because we have very old-fashioned thinking.
>
> And if you can have a good relationship with your doctor, even better to discuss what you're finding and what you're thinking. They can say, that's rubbish and this is why, but you need to be able to have that two-way dialogue. And I think if the health professionals are unwilling to have a two-way dialogue and be a partner in your health, then it won't work. **P13**

This was supported by other participants who felt some HCPs were against the internet for health information seeking, and they did not feel comfortable sharing their internet findings with their HCP as they did not want to undermine their HCP. Therefore, some participants accepted the paternalistic approach as they felt that it was more appropriate.

> I would be annoyed if somebody came in and told me how to do my job. **P10**
>
> I wouldn't show them. I don't want to aside from what they're going to do in their treatment. I want them to still be able to do their job without me saying, well, this is what the internet says. I want to let them make their own decision **P15**

Participants reported using the internet for health information not to challenge their HCP, but to engage in better discussion and to build a partnership with them. One participant reported,

> The idea that the patients are trying to do the doctor's job needs to just go. Because obviously that's not what people are trying to do because they are still going to the doctor. **P16**

7.3.4.3 Healthcare professional behaviour, characteristics and reactions to internet-informed patients

There was a mixed response amongst participants when asked if they share their internet findings with their HCP's. Most participants identified certain behaviours and characteristics of their HCP which determined whether or not they would feel comfortable sharing their internet findings and research with HCPs.

> I have in the past. And I've been dismissed and just ended up getting to the point where I've even said to the doctor, I'm not going back to that consultant, I find their manner very patronising and dismissive, and they refuse to have a broader discussion about what the levels mean. **P13**

> Reasonably comfortable, it would depend on who I see really. **P14**

Participants felt reassured when presenting internet health information to their HCP, and the HCP acknowledged their findings and took time to discuss the information with them and offer their opinion on it.

> My GP was very understanding. And she would go through reasons why she thought it wasn't whatever I was suspecting. And go through the points why it couldn't be that from the test that I had. So, she was very good and thorough, going through everything with me and making me feel like I wasn't wasting her time. **P9**

When a negative response was received from the HCP, it brought discomfort to some, especially having to continue the consultation discussing personal health but feeling uncomfortable and shut down.

> I think it just makes me feel more uncomfortable being there because I'm like, well, they've already been a bit rude and angry to me like I don't really feel that comfortable talking about my health, my personal health. **P16**

Some participants had the impression that HCPs had negative preconceptions of online health information and self-diagnosis which made them more cautious to share their findings.

> I think the doctors are quite dismissive of any internet searches or any information that you pull up. They think, oh just ignore that, take your medication like a good little patient and do what you're told. And I think it's quite a paternalistic, patronising way they talk to you sometimes. I think the model in Britain is very much that old-fashioned paternalistic model of the GP is God, and the consultant is God, and they will make decisions. And I've had this in the past with my experience in the healthcare system in Britain. **P13**

7.3.4.4 Trust

Trust was usually built on analysis of the HCP behaviour and reactions towards the patient which included their communication style, feeling listened to, and receiving the correct diagnosis. A 'healthy mistrust' in HCPs was described by one participant as although HCP's have the knowledge, they do not understand the depths of an issue or the pain of a symptom unless they have experienced it. In this sense, this made the internet an appealing source to connect with others who do have that understanding.

> I feel like sometimes I have like a healthy mistrust of people who are like professionally trained but never actually experienced the issue because like, you can't possibly know the depth of an issue unless you experience it. And so, I feel like online you can find out. It's like in the doctor's office of course, more knowledge, but I'm not sure they have as much knowledge of the experience of it. **P16**

Participants reported that feeling listened to was important to them. It helped form a better relationship built on trust and understanding, as opposed to those who did not feel listened to, which resulted in feelings of neglect which can lead to having a negative impact on the relationship.

> Sometimes I feel that relationship breaks down when they're not willing to listen to the patient that says to them, this is what I know from my own body and what other people are saying the same thing, and I want to try

> this, and I don't want to take that intervention because of x, y and z. I've got concerns about that. **P13**

One participant reported an increased trust in their HCP when the HCP confirmed a diagnosis they had earlier arrived at through their prior online research.

> When my doctor told me the diagnosis, that I had an endocarditis, I was not surprised. So, this gave me some security so I had the feeling, okay, I can trust my doctor. I know this might sound ridiculous, but I researched, and I had the idea, okay, it could be an endocarditis, and when my doctor told me yes, it is probably exactly this, I thought okay, she comes to the same conclusion I came to; I think I can trust her. **P4**

However, mistrust was caused when participants disagreed with their HCP or received a wrong or no diagnosis. At this point, they would seek online health information, or some respondents reported that they changed practitioners to get a second opinion.

> I'm quite cynical about doctors because I believe the heart attack was caused by them not picking up on what I was telling them for about 25 years. So, I'm very cynical about the medical model of me as a prescription patient. Because you think, well, you never listened. **P13**

Most participants trusted and valued their HCPs opinion above all other sources. Some participants did not share their internet findings with the HCP because they trusted their HCP to give them the correct diagnosis regardless of their internet search.

> I went in there, didn't even tell them I'd looked at the internet, I just told them my symptoms. And maybe because I wanted ... I guess because I was a bit distrustful of the internet, and I was more trusting of the medical professional. Maybe, because I want them to think they're my first call. **P6**

One participant reported feeling trustworthy of nurses as they felt nurses believed their symptoms more and would take time to listen to them,

> We had very nice nurses in the clinic. The nurses are, most of the times, the ones who believe me and say, okay we will do something. So, with the nurses, I sometimes trust more than the doctors. **P4**

Participants often brought up their respect for HCP training and medical expertise and how the HCP had been trained to deal with these health situations, in contrast to themselves.

> I mean you still trust what they are doing and if anything, I think it gives you more respect. Because you realise how many different illnesses and symptoms and how they've got all that information in their heads. So, yeah, I think it makes you trust and respect them more because you think all this information. Like you can Google all you like and search all these different illnesses, but at the end of the day I will still respect anything that a healthcare professional tells me. **P15**

7.3.4.5 Time constraints

Time constraints was frequently reported as a reason people were drawn to the internet for health information. Participants reported often feeling rushed within the healthcare appointment and not having enough time to discuss what they had hoped for.

> He's always in a rush, like, next person's in in ten minutes, I've got to do this quick and get you out, kind of thing. **P1**

Feeling rushed in an appointment often led people to not feeling reassured with information received and not feeling listened to, which can cause mistrust. It was understood that HCPs work within timeframes in order to attend to all patients; however, it was still a frustration for most participants.

> It would be nice if they weren't so busy, because it feels like they are just trying to, like, push you out the door, because they need to get to the next patient. So, having, like, a little bit more time with them, allowing them the time to spend with you so that they are not just shoving you out of the door and they can actually listen to you, because I know that they are really busy, you know, I guess there's not enough people that, yes, just more care. **P12**

> If I feel like I'm at a doctor's appointment where I'm, you know, in and out and I know they've got a million people in the waiting room, I might not trust what they've said, and I might go back to doctor Google. **P6**

One of the downfalls with time constraints is not having the opportunity to discuss holistic aspects around the diagnosis.

> When you finally get an appointment for the doctor, you're in and out in five minutes, and they don't really ask about holistically what's going on with you. And I was looking for answers that were holistic. **P13**

7.3.5 The information impact of COVID-19

The COVID-19 pandemic brought public health to the fore with media outlets providing daily updates and dissemination of health information surrounding the global outbreak. It is important to understand the impact COVID-19 had on individuals' access to healthcare and their use of using internet resources for health information. This theme consists of several sub-themes including access to services; living with cardiac conditions during COVID-19; and dissemination of COVID-related online health information. These relate to the NPT theoretical construct of reflexive monitoring (appraisal work) as it evaluates and reflects upon the usefulness of the internet during COVID-19. Each sub-theme will be discussed with exemplars provided to illustrate the meaning of each sub-theme.

7.3.5.1 Access to services

COVID-19 has had an impact on how people access health information. This was discussed by participants as their access to healthcare had changed from face-to-face to self-managing online health resources and telehealth.

Primary healthcare services moved many appointments to telehealth services. Some participants described this as not being as efficient as they hoped, as they did not feel the HCP could truly see and understand the effects of their symptoms.

> My stepdad has been sick all this time with other issues and, like, we couldn't get anyone to really see him. His doctor would just, you know, do Facetime but nothing came out of it because she didn't really see how he was. It was just, like, okay, well, like, let me know how you are in a week and then it got to the point where we had to take him to the hospital. If you actually have an issue that you want to get checked out, it's frustrating, like, not being able to go. **P12**

Some participants explained they were not using healthcare because they were unsure of whether their problems were worthy of visiting a HCP during such unprecedented times, and therefore, relied on the internet as their main diagnostic source.

> Honestly, I’ve not spoken to any medical professionals about COVID apart from the nurse over the phone. I have just been using the internet for COVID and medical information. **P16**

In the UK, media coverage informed the public that the NHS was still open and people who were suffering any health issues, should still use these services. However, many participants did not feel that services were available, nor did they feel comfortable visiting them. Some participants had feelings of guilt because they did not know if their condition was serious enough to attend healthcare services during a pandemic.

> I find this not to be the case. A lot of people are trying to get seen but haven’t been able to. **P14**

> So, I did think about contacting him, but I think with all the COVID going on, your lost to contact with them because you think they might be very busy with COVID, and you know. I do feel guilty because I hate shielding, I hate the restrictions, but then you see these people lying in bed on ventilators and then you feel guilty because you just think “well I’m safe”. **P14**

7.3.5.2 Living with cardiac conditions during COVID-19

Having cardiac issues was classified as being vulnerable to COVID-19, which caused fear, frustration and confusion amongst other emotions. Participants who were diagnosed with cardiac conditions, explained their perceptions.

Anxiety was experienced by participants with cardiac conditions throughout the pandemic. They were afraid they would develop any complications with their condition and had to be admitted to hospital or require medical services. They wanted to avoid this due to their risk category.

> So that was quite stressful to begin with and probably spiked my anxiety in relation to the condition. Because then you’re thinking, just please don’t have any heart twinges, don’t start having back pain or jaw pain and stuff. So that probably did spike things mentally. **P2**

Participants also felt confusion regarding lifestyle aspects, especially at the beginning of the pandemic. For example, if they should still go to work. There seemed to be mixed suggestions and no straight-forward answer.

> For weeks I was very, very insecure. Am I at risk? Should I go to work? Should I keep working with children? Should I not? My cardiologist said no, don't do it. My GP said okay, try it. I was very, very insecure. I don't know when they published this information. It was weeks into the pandemic. **P4**

Participants expressed confusion about the dissemination of information about heart conditions and COVID-19 when the pandemic initially started. It was announced that they were in a high-risk group, however many were not sent letters which suggested they needed to shield at home. Therefore, they did not understand if they were still classified as high-risk or if they should shield based on their own judgement. They felt the information was unclear online and offline.

> Because at the beginning, people said well, patients with heart issues are at a higher risk. And then I read only patients with heart conditions like this, and this are. And another source had heart conditions like this or that. And I never knew if it was really relevant for me or not. **P4**

Conflict had arisen on online health forums and social media support groups when people were posting whether they had a letter or not, which led others to judge their situation against theirs.

> I think it's shielding and being frightened; a lot of the people are frightened. You know, some of the people on the forum, they're scared and especially at first lockdown when there was so much going about, and I think people are scared and frightened. Some people were under pressure to go to work even though they should be shielding, and they had financial worries. So, I think there was an awful lot of anxiety and then people got angry because someone with the same condition as they had, got a letter telling them to shield and they didn't. I mean I didn't get a letter to shield until about a month into lockdown, you know. **P14**

> Knowing that I should be shielding but don't have a letter. You think am I a fraud? Am I reading too much into this? **P2**

The participants that shielded said they did not feel online information was disseminated clearly enough to the rest of the public about the severity of the pandemic. One participant reported feeling alone and upset as she stayed indoors and was frightened of leaving due to having a heart condition and watched people break lockdown rules.

> When I see people not wearing masks and not taking any precautions, I'm really getting mad because I can hardly leave my flat for anything if people are running around spreading the virus. It's frustrating. I'm also very sad because when I meet my best friend – she just really struggles to understand this – I'm really disappointed. **P4**

7.3.5.3 Dissemination of COVID-related online health information

Discussions around the quality of health information were explored. Some participants felt that the information distributed was concise and clear considering this is a health crisis we are all facing at the same time.

> I think its excellent the way that its being explained to us that people with heart conditions or other people who may have lung diseases or diabetes, have to be really extra careful in terms of shielding and what they can and can't do, I think that's really important. **P11**

> Yeah, I think it's been good. I think it's been hard for it to be any better than what it already is because it's such unknown circumstances and an unknown illness. I don't know if it can be any better than what it already has been. **P15**

Many participants found themselves switching off the news and information outlets as it became overwhelming. Health concerns had never been more televised than now, and this began to impact people's mental health. Therefore, they were still abiding by rules and following updates, but began to switch off mentally from COVID-19 online health information.

> I turned off all my news outlets and stuff because I was so obsessive. I even, jumped off social media for a couple of months because I was just too obsessed. I was just so paranoid. I was just feeling bombarded. **P6**

> I have tried to limit the amount of exposure for myself because it's just been worrying. There's only so much worrying I can do in a day. **P10**

People discussed resources they would regularly use for updates on their heart conditions, and how such sources became helpful when combined with COVID advice,

> Going back to British Heart Foundation, I went back to reputable sources. So, I know if they're putting out something, I know I'm going to be reading that and looking at it. They were quite helpful in that they broke it down… Instead of having, like, shielding or not shielding and, kind of, one or the other, they broke down the heart risks into three subsections, so very high risk, high and whatever. There were three you could look out for. So that was really helpful to see that information, to say well I'm not really, really high risk but I am high risk, so therefore you're almost stratifying yourself. **P2**

Participants who had experienced COVID-19, and who were now experiencing long-COVID, had struggled to find information regarding their symptoms as most of the published information discussed people who were hospitalised with COVID as opposed to those experiencing milder symptoms and long-COVID. One participant described there not being any public information available that she found helpful. However, she found social media support groups that connected her with others also suffering with long-COVID, and suddenly found she was part of a community and no longer on her own. She found the social media support groups to be the most help she had since experiencing long-COVID symptoms.

> I find it so comforting, especially with the long COVID stuff with smell and taste loss. That was so weird to see that other people have these symptoms. Especially because I read so many places online that the doctors and nurses don't actually know how to treat it properly yet. And to be honest, I don't know if that's 100% true because I haven't been to check. So, it's good that other people are in that situation. I felt like I was crazy or making things up. I didn't have anyone around me, especially with COVID because it's such a new thing. The things that I was saying, people were like, really. But then when I found other people that had the same things I was like, I'm not crazy. I've been online and read so much stuff about it and seen other people who are experiencing the same as me. **P16**

7.3.6 Summary of public perspective

Part one of this chapter gathered the public perception from sixteen participants about seeking online health information and self-diagnosis. The themes explored motivations of people using the internet, hesitancies they had when seeking health-related issues online, the understanding and uses of online health forums, information sharing with HCPs and the impact COVID-19 has had on their relationship with online health information.

Summarising key points found within this chapter - public participants hoped for their HCPs to recommend resources and acknowledge their health concerns around not only physical symptoms, but also mental health, social and spiritual needs, normally as a result of their physical symptoms. This was reported to be one of the most common reasons why people were led to the internet, because they did not have enough time to discuss holistic aspects with their HCP.

American participants highlighted issues that they not only had to worry about their health but also their financial status. The internet was used as a primary healthcare source for all American participants included in this study and ultimately, used the internet to make informed decisions about accessing healthcare services. Although all participants reported having health insurance, issues were still raised such as having to pay the cost before being reimbursed.

The use of online health forums and social media support groups received a mixed response. People with diagnosed heart failure and long-term conditions seemed to have a more positive perception. They found it helpful that they could access an online space to others having similar experiences. However, many participants, mostly those who did not have a diagnosis or confirmed heart condition, were wary about using such a resource due to not being able to see who is providing healthcare advice, and not being able to know how accurate the provided advice is. This suggests such a resource may be more appropriate for people with long-term conditions or a confirmed heart diagnosis.

Sharing online health findings with HCP's received a mixed response. Some participants felt optimistic about sharing their findings with their HCPs in hope to work in a partnership and make informed decisions together. Others reported not wanting to overstep boundaries and to respect their HCP's opinion above all other sources and felt it was unnecessary to share their internet findings. One important finding was that the HCP's behaviour towards an internet-informed patient, was ultimately the decision-maker of whether that person felt comfortable sharing their findings or not.

Finally, the impact of COVID-19 has ultimately increased people's internet use for seeking health information. Although healthcare services were open, people reported not feeling comfortable to attend them, especially when there may be others more in need or they felt worried to attend appointments. Most participants found the online health information to be clear and concise considering everyone was learning about this virus at the same time. However, some information became overwhelming for people which led them to taking breaks from social media. In normal circumstances, online health information seeking was in the user's control, and they were able to opt in and out based on their own accord. However, COVID-19 online health information has been disseminated over all media outlets and participants reported that it was almost impossible not to be reminded daily. All participants reported that the internet had become one of their main and primary sources of healthcare during the pandemic.

The next section of this chapter will explore the perceptions of HCPs about patients use of the internet for seeking health information and self-diagnosis.

7.4 Healthcare professionals' perceptions

Six major themes (positive perceptions of patients' online self-diagnosis and health information seeking; negative perceptions of patient's online self-diagnosis and health information seeking; adopting behavioural approaches; recommending resources; the impact of COVID-19; and the impact on relationships) and several sub-themes were identified from the analysis (Table 7-5). Data were thematically analysed and conceptualised using the NPT framework. As with the public findings, the participants were identified by pseudonym. However, nurses will be identified as (HCP-N1), doctors as (HCP-D2), and allied HCPs (physiotherapists and physiologist) as (HCP-P3). Exemplars are included within each sub-theme.

Table 7-5: Themes and sub-themes

Themes	**Sub-themes**
Positive perceptions of patient's online self-diagnosing and health information seeking (CO, CA)	• Patient empowerment • Learning from informed patients • Accessibility
Negative perceptions of patient's online self-diagnosing and health information seeking (CO, CA)	• Challenged • Premeditated diagnosis, treatment and decision-making • Interpreting findings • Health anxiety
Adopted behavioural approaches (RM, CP)	• Setting realistic expectations • Active listening and acknowledgement • Patient approach • Communication
Recommending resources (CA)	• Positive perceptions of online health forums as a resource • Negative perceptions of online health forums as a resource • Recommending online resources to patients

The impact of COVID-19 (RM)	• COVID online health information • Everyone is an expert • Healthcare services
The impact on relationships (CP, RM)	• The nurse-patient relationship • The doctor-patient relationship • The allied HCP-patient relationship

7.4.1 Positive perceptions of patients online self-diagnosing and health information seeking

The theme of positive perceptions of patients online self-diagnosing and health information seeking arose from the prompts, “have you experienced internet-informed patients in appointments?” and, “how do you feel about patient’s presenting their online health information to you?” This theme relates mostly to the NPT constructs of coherence (sense-making work) and collective action (enacting work). Figure 7-3 presents positive perceptions from HCP participants of patient internet use for health information.

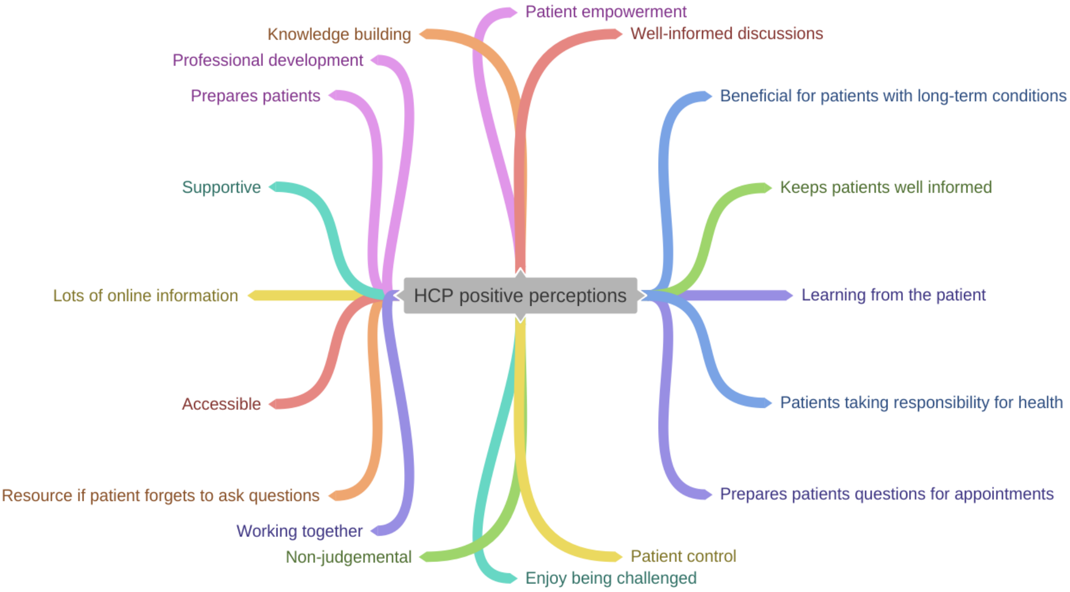


Figure 7-3: HCP positive perceptions

7.4.1.1 Patient empowerment

Patient empowerment was the most frequently reported benefit. HCPs felt having access to online health information allowed patients to have more control over their health and to feel better prepared for their appointments.

> Another big thing is empowerment for themselves. So, they would feel like they're not so vulnerable going to someone absolutely helpless. I think it's human nature to try to avoid that feeling. So, if they can come in appearing to be a bit more informed, it's just going to make them feel a bit more at ease and not as helpless. **(HCP-P10)**

Patient's having more knowledge allowed for better informed decisions to be made between the patient and HCP.

> They're just looking for firm information. You know, knowledge is power at the end of the day. They want to feel like they're in charge of their own care and that they're making the correct decisions about their care. **(HCP-N9)**

7.4.1.2 Learning from informed patients

The expert patient was defined as someone who was well-informed about their health, or someone who had specialised knowledge about their condition as it is personal to them. HCPs felt that many patients were able to stay well-informed by having access to a wealth of online health information which some described as being a good challenge to their expert knowledge as well as being a guide for patients to ask efficient questions, as one nurse explains,

> I think there are a lot more informed patients now. And I think that's probably a good thing because I think it challenges health professionals to dig a bit deeper when we're talking to patients and really provide every bit of information. I think it makes you take time with your patients and really help them understand, and it guides them to ask the right questions. **(HCP-N14)**

As expert patients search their conditions online, they become more knowledgeable about their condition, in addition to their knowledge of the lived experience. This was considered valuable and important to the HCP knowledge as one physiotherapist explains,

> Some of them that have lived with the disease for a long time, or they've got congenital heart disease, or they've got some rare conditions. They know more about their illness than I do, they know more about everything else. And it's almost using them as a teaching opportunity. It's like, right, tell me about it, how does that react with this. And it's a really good learning opportunity for my students that come in and my junior staff. The patients know the ins and outs of this, they're possibly involved in different charity work, they're involved in different support groups, learn from them. **(HCP-P6)**

HCPs reported benefits of improving their professional development when patients presented them with findings they had not yet come across. They expressed the importance of not only learning from textbooks, but also learning from patients.

> I love it when people come in with new information that I might not be aware of. It allows me to go out and do a bit more professional development in my own time and reflect on those consults and it furthers my learning in that sense. If they've got different conditions they've lived with their whole life, give me the links and I'm here to learn. If it's something I've not seen before, I want to know about it, I want to learn so that when the next patient comes in with that, I've got better skills to relate to them. **(HCP-P10)**

7.4.1.3 Accessibility

HCP participants felt that the accessibility of the internet was valuable for patients. It was a resource people could use freely, at any time and was non-judgemental. It was also accessible in terms of being a resource people could use when they were unable to book or attend a HCP appointment.

> I think it's very, very related to maybe feeling being judged when you arrive. And that allows you for going the easy way out which is probably consulting Google which is never going to judge. I think it could be related to that, so easy access and not being judged by a person. **(HCP-D1)**

> It’s easily accessible. So, rather than people having to wait to book in with their GP or go to the hospital, things like that. It can be a quick go to, to get information about their condition or symptoms, so I think that’s an advantage of it. **(HCP-P15)**

HCPs felt patients having access to the internet allowed them to better prepare for their appointments as well as being a convenient tool post appointment for further information gathering.

> I think sometimes people get a bit lost in the jargon, in the medical terminology when they’re talking with doctors and nurses. And it can be a bit overwhelming when you’re in the hospital phase. So, having the option to go home and do your own independent research, I think is quite helpful. **(HCP-N14)**

7.4.2 Negative perceptions of patients online self-diagnosing and health information seeking

The theme of negative perceptions of patients online self-diagnosis and health information seeking arose from the prompts, “Have you experienced internet-informed patients in appointments?” and, “How do you feel about patient’s presenting their online health information to you?” This theme relates mostly to the NPT constructs of coherence (sense-making work) and collective action (enacting work).

Figure 7-4 presents HCP overall negative perceptions of patient internet use for health information.

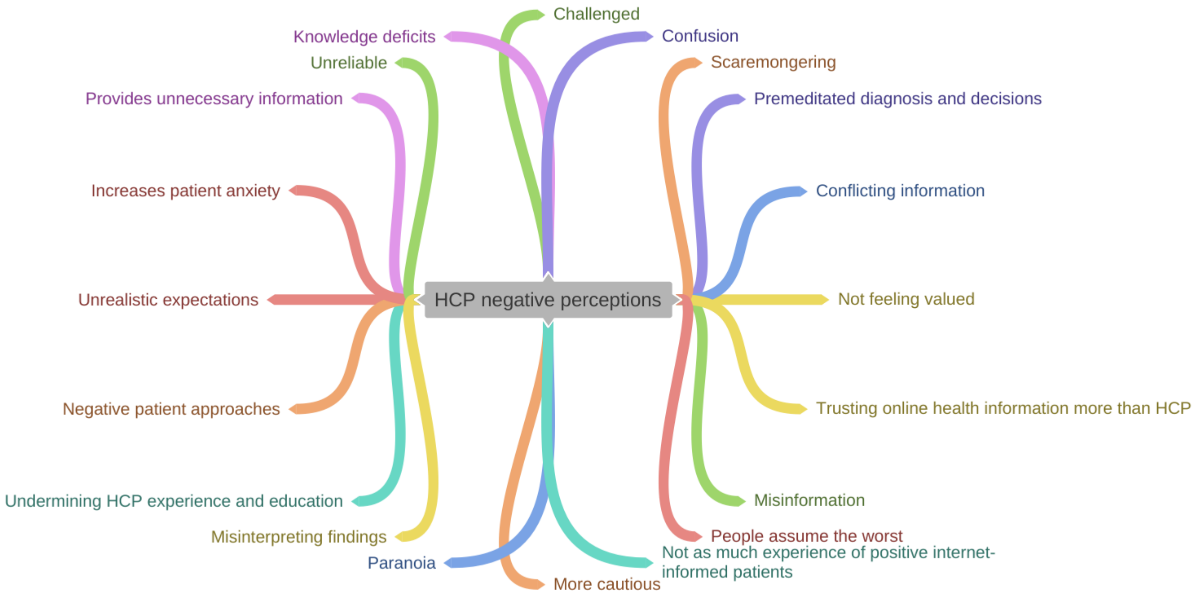


Figure 7-4: HCP negative perceptions

7.4.2.1 Challenged

One of the most discussed negative perceptions was HCPs sense of feeling challenged by patients. HCPs felt some patients would attend the appointment to challenge and oppose their opinion, making them feel undervalued. Some felt their expertise, experience and education was undermined when a patient presents more trust in their internet findings than the HCP’s opinion. Several HCP participants reported feeling challenged by having to prove their expertise in comparison to internet findings, more so than feeling challenged from the patient themselves.

> Not everyone is a nurse or a doctor or a health care professional because we had to train to do that job and get the experience, the years of experience that culminates, and you’ve been able to care for somebody and not just go on the internet and find out how to do it in a day. So, it’s that kind of difference. **(HCP-N12)**

> Initially I feel, it makes me quite frustrated because it makes me feel that they’re not listening to me as a clinician as an autonomous practitioner.

> They're not valuing my years of clinical experience. So, they value what they've read online more than my clinical experience in my job. So, it can be quite frustrating at times. **(HCP-P15)**

7.4.2.2 Premeditated diagnosis, treatment and decision-making

HCPs recognised and understood that many patients may have conducted online research before attending their appointment. However, this led to some patient's attending appointments with a preconceived diagnosis and treatment options. Preconceived decision-making presented to be a challenging task when HCPs did not agree with the patient's research. Furthermore, several participants felt that some patients would only attend HCP appointments to reaffirm their preconceived decision from their self-diagnostic process.

> There's a couple that come in with a pre-requisite of what they think they have and it's very difficult in my opinion to change their minds. They have their minds set on what it could be, and you have to talk them down to what it is or what it most likely is. **(HCP-N3)**

This caused the healthcare diagnostic process to be disrupted as the normal routine would be to listen to the patient's symptoms, perform appropriate tests and base judgement on clinical decision making and evidence-based practice, before deciding a medical pathway for that individual patient.

> In the medical profession you rule things out. You start to rule out what it could be and what it isn't, like testing for different things… It's now changed how you diagnose people because they are giving you information and they are probably influencing the way that you would go about their treatment plan because they've already got this picture in their mind, or maybe they've already got their diagnosis in their head. **(HCP-N5)**

Patients' seeking online health information can also lead to the expectation of unrealistic treatments for their care. HCP participants described scenarios where patients would attend appointments and tell the HCP the treatment they believe they should have as a result of their internet findings. When the HCP did not agree with the information, it led to further questioning of the HCP's clinical decision.

> People are just going for the most extreme diagnosis and then wanting the specific treatment for this extreme diagnosis, and it's just not attainable in our kind of NHS infrastructure. **(HCP-N3)**

One nurse explained approaches she adopted when communicating with patients who have unrealistic healthcare expectations. One being to signpost the patient to a second opinion or a resource, to provide them with reassurance and validation of her advice.

> Again, more 'I could have this, or I could have that'. And it's like, you could have but, none of our examinations are pointing in that direction. You can always say to a patient, and I always do, that you are more than welcome to get a second opinion. But I think some patients can leave quite disgruntled that they didn't get what they want based on what they've read. **(HCP-N3)**

HCPs found difficulty in explaining to patient's why they are unable to do certain procedures or tests that patients requested, as they have medical diagnostic models, protocols and guidelines which they are required to adhere to.

> That can be quite challenging as a care provider to convey that we have protocols in place that you don't know, and they're there for a reason and most investigations we do are to disprove things rather than prove things. So, we wouldn't do specific tests in the emergency department that they want, and it wouldn't be in the kind of timely manner that they want it. So, yeah, quite intimidating. Quite challenging. Very much mental judo. **(HCP-N3)**

7.4.2.3 Interpreting findings

HCPs found themselves often having to interpret the patient's internet findings. This was either due to patient's misunderstanding the research or explaining why their findings was not their confirmed diagnosis. One physiotherapist explained that they try to provide education in this type of scenario,

> Sometimes patients come in and they have diagnosed themselves and it might not necessarily be the right diagnosis. So, they are the ones you have to worry about a bit more because you have to do a bit more education and you have to try to convince them otherwise. That maybe the information that they looked at, or that first link that they clicked on, wasn't actually correct and did not actually reflect their symptoms. **(HCP-P10)**

One doctor explained an experience of younger patients misinterpreting heart attack symptoms,

> I had a couple of patients who had come in who were quite young and who had chest pain but didn't really have any risk factors for having had a heart attack. So, they were all low risk but have heard or read about things to do with heart attacks and have convinced themselves and are scared. Obviously, that's a scary thing to experience, chest pain. But perhaps the information they are reading is more directed at people with a high risk of having cardiac issues. Them coming in and having a normal ECG and reassuring blood results and then they're still really worried that they're having a heart attack and you're trying to explain, they're 30 years-old, you're not going to have had a heart attack, can be a bit challenging. **(HCP-D2)**

HCP participants discussed concern that re-interpreting findings before examining the issue themselves to be challenging when time in consultations is already limited.

> If you've got 15 minutes for an assessment with a GP patient and you're spending 15 minutes explaining why you're not doing a certain examination or test for a specific diagnosis, then that's your whole time. **(HCP-N3)**

HCP participants felt they had to explain their clinical decision-making and provide patients with evidence of how they reached their decision. They found this helped to reassure patients and build trust in the relationship. However, this came with added pressure on the HCP role and further issues with time.

> I'm having to explain myself a lot more. And it puts me kind of on the back foot sometimes because you've really got to be hot on your evidence. Because I think the next thing will be like, 'well, why, you need to tell me more'. So, you need to be able to present the exact correct evidence to them and say, well, actually this is the evidence-based advice. **(HCP-N9)**

7.4.2.4 Health anxiety

HCP participants shared concerns that self-diagnosis could cause anxiety or distress for some patients. When an individual is not trained in interpreting clinical information or making decisions based upon clinical judgement, it can lead to misunderstandings, misinterpretations and increased worry and anxiety.

> Say for instance someone that's a hypochondriac, or just someone that's more aware of their sensations of their body or something. They might enter these symptoms into the internet, and these symptoms could apply to hundreds of different illnesses and then it'll manifest itself as a kind of mental health issue. **(HCP-N12)**

Often, anxiety can be misinterpreted for cardiac issues. This can lead to patients admitting themselves to health services when they may not need to.

> I think there is an emerging low-level anxiety that I think a lot of people suffer from. I think that can be conflated with health anxiety and people can transfer their anxieties with other things into their own health and it becomes like a self-fulfilling prophecy. If they are anxious, they have a panic attack and they look up their symptoms and think they have a cardiac issue and they come in. **(HCP-N3)**

One emergency nurse practitioner explained that she felt there was a higher prevalence of health anxiety and self-diagnosis in the younger generation,

> I think there's definitely a health anxiety among younger people now, that wasn't there in the previous generations. But I don't know if that's because of access to the internet. I see a lot of young people thinking they have diseases that are very rare in young people and its usually down to anxiety. **(HCP-N3)**

7.4.3 Adopted behavioural approaches

HCPs discussed adopting slight behaviour alterations towards internet-informed patients. All HCP participants said they would treat every patient the same, regardless of their health information-seeking behaviours. However, they felt they had to alter the way they approach and communicate with internet-informed patients, which is further explained in the following sub-themes: setting realistic expectations; active listening and acknowledgement; patient approach; and communication. This main theme arose from the prompt, “How would you normally react to patients presenting with online information?”. The theme was mostly related to the NPT constructs, cognitive participation (relationship work) and reflexive monitoring (appraisal work).

7.4.3.1 Setting realistic expectations

One approach that HCP participants described adopting was setting realistic expectations. Often, patients would already have developed ideas of what their diagnosis may be, and the treatment that follows it. Therefore, HCPs explained that being honest and setting realistic expectations from the beginning, was integral to the productivity of their relationship. Setting realistic expectations often came hand in hand with effective communication skills, as described by one emergency nurse practitioner participant:

> So just setting the expectation, the realistic expectation at the start of the conversation. Also, having each point in the patient’s journey explained to them as well. So, they’re not left to think about things and then told ‘oh yeah, we don’t think it’s anything, go see the GP, bye’. You know, it’s not answering their questions and it’s not keeping them in the loop, and I think that’s taking the control away from the person who’s probably very anxious and is seeking to gain a better understanding and control of the symptoms they’re having. It all comes down to control. **(HCP-N3)**

Setting realistic expectations with patient’s is important however, as the access to online health information grows, it can become more difficult to manage those expectations.

> It’s just managing realistic expectations and the bar is set much higher now that people have a lot more access to clinical information. **(HCP-N3)**

7.4.3.2 Active listening and acknowledgment

HCPs highlighted the importance of active listening to ensure the patient feels heard and listened to. HCP participants reported a sense of duty to listen and acknowledge the patient's online findings since the patient felt it was important enough to share them.

> I think it's all about making sure the patient feels listened to. **(HCP-D1)**

> Every patient is individual as well. So, you need to take individual preferences. So, not just treating the condition, but treating the patient in front of you is really important. So, one thing that might work for one person might not necessarily work for another. And it's our job to kind of identify those different factors. **(HCP-P10)**

One nurse reported the importance of listening and responding to patients on a level where they feel comforted and reassured,

> I would always treat them the same. But also, just being more aware and speaking to them, like on a more level ground. Just make sure I'm not patronising them and not maybe undermining their beliefs and what they've read and just being conscious of that. **(HCP-N12)**

Several HCP participants reported that they preferred to know if their patient was seeking health information online and hoped that their patient would share this information with them. Some participants reported that it helped them to have an insight into the patient's pre-conceived understanding of their symptoms. They believed it could have further insight into representing how the patient truly feels.

> I looked at exactly what she had found, and I went through it with her and said well this I agree with and this, you know in terms of your situation, like this part applies but the other part doesn't apply. So, I like to work, I guess tailor what I'm saying around the pre-existing information. Which I would do anyway, but if its internet then I would go to the internet then look up what they found and that kind of thing. But I'm usually glad they've

> told me about it. I'd rather they come and tell me about it than them do it and me have no idea that they're doing it. **(HCP-D4)**

7.4.3.3 Patient approach

How a patient approaches HCP's with internet findings, determined how the HCP would respond. HCP participants reported feeling open to having informed discussions with patient's who wanted to understand more about their condition. However, if the patient attended the appointment in a confronting manner with their internet findings and seemed to be wanting to prove the HCP wrong, HCP's reported adopting a different approach and they felt more challenged and slightly frustrated. However, all HCP participants reported their main goal was to reassure the patient in their care.

> I mean it just depends on how it's presented, I suppose. If you have a patient who has come to see you and they're worried about something because they've looked it up and they want to talk about it, that just makes me feel like, okay let's have a discussion. But if there's somebody that's come to you that's a bit aggressive and is angry and upset because they've read some information online, obviously that makes me feel a little bit threatened. But still the end goal is we have to talk about what information they've found online and try to diffuse the situation a bit. I guess you just have to have a discussion but sometimes it can be tricky if somebody is a little bit angry or upset. **(HCP-D2)**

7.4.3.4 Communication

HCPs found communication methods to be key when trying to establish the patient's understanding of their condition or findings. Acknowledging the patient's understanding at the beginning and end of the consultation, was suggested as a way to achieve effective delivery of patient education and to reduce misinformation and misunderstandings.

> It is important to find out what information has been passed on to the patient about what their condition actually is, how it has manifested and how it's being discussed and explained to them, which quite often it's not and they pick out certain words and that's all the patient remembers, and they'll go and look up that bit. **(HCP-P6)**

Participants highlighted the importance of communicating with patients in layman's terms and reducing the medical jargon to eliminate potential misunderstanding that could lead to seeking inaccurate information. HCPs reported trying to assess a patients' health literacy to ensure they were communicating effectively with each patient.

> I'll have to explain it in terms that I think they understand because they could interpret what I say differently. **(HCP-N13)**
>
> I think that changes the approach as to how you talk to your patient as well because sometimes when you are not clear, the patient is very, very likely to find out by himself on Facebook or Google. And that can lead to many other things like, misinformation. **(HCP-D1)**

7.4.4 Recommending resources

All HCPs were prompted with "do you provide patients with online resources?", and "what are your views on peer-to-peer healthcare on online health forums?". HCPs provided reasons for and against recommending online health forums and their methods of guiding patients to reliable online resources. This theme relates mostly to the NPT construct, collective action (enacting work).

7.4.4.1 Positive perceptions of online health forums as a resource

HCPs felt online health forums could be a useful resource for people with heart failure, long-term or rare conditions when it was used for support and not diagnostic advice.

> Maybe for heart failure or carers type stuff. Like more of a support thing rather than an advice thing. So, like you know sufferers of some sort of specific genetic condition, I think they find a lot of support by gathering together because there's only 500 of them in the world, that kind of thing. That I'm all for, but as a support peer to peer rather than advice. **(HCP-D4)**

HCPs described the term 'peer specialists', for people who had been living with a condition or had experience caring for someone with the condition. They felt such patients would be helpful to contribute to online health forums as it could help others to not feel alone, and the advice comes from those who are living the same experience.

> By nature of the relationship I have with patients, I don't know what it's like to live with their condition or how it impacts their life and I think that that's really important. Particularly if, just in their natural circle of friends and workmates, they don't know anyone else with the same conditions, then I think it's very positive in the right environment for that support. **(HCP-N7)**

Overall, most HCPs found online health forums to be a useful resource for supportive purposes and to meet others who shared similar experiences.

> I think it's wonderful if you can talk to people that have shared the same experience as you and if they can help guide you for what is to come and to expect. I think that's really wonderful and very comforting to patients to have that. **(HCP-N14)**

7.4.4.2 Negative perceptions of online health forums as a resource

Negative perceptions were also shared when discussing online health forums. Many participants felt that experiential information was unreliable as what happens to one individual, may not be experienced by anyone else. They also felt that most people would only use such forums to report their negative experiences as opposed to a positive one.

> It's a tricky one because like I say, it's hard to think that you can trust something that other people wrote because everyone's different. And everyone's bodies different. So, someone might have a problem with the heart, but then someone else might have the same problem with the heart. The bodies are going to react very differently. So, by using an online forum like that, you know, I think it could be a bit scaremongering. **(HCP-N11)**

Concerns regarding potential for negative impact on mental health were also raised. HCPs felt that online health forums could be an intense environment and lead to increased anxiety and potential mental health issues.

> It can be bad in the way that they just spiral into it. It's just like this negative spiral of that hypochondriac kind of situation. Two might be talking together and just it's just like a ticking time bomb, you know what

> I mean? And whatever's going on with them at the time, they'll probably just exacerbate or make worse because of the stress. **(HCP-N12)**

HCPs also had concerns that the information provided on online health forums could come from anyone. There are no credentials for who you are speaking to, and they felt concerned that people could be seeking advice from others who were not qualified to make these types of clinical decisions.

> We don't know where the information is coming from. It can be coming from anyone. We don't know if it's evidence-based information or if it's anecdotal. So, one thing that may work for one person and then they're going online and saying, this, this and this works for me, so, this must be the right answer. It might not necessarily work for the other person. **(HCP-P10)**

As online health forums can be accessed globally, potential concerns were raised about patient's wanting healthcare services that were not available within their country, as explained in a typology from an emergency nurse practitioner,

> If it's globally, or even nationally, then treatment differs from area to area and health board to health board. So, I think patients demanding is a bit of a postcode lottery sometimes, in the UK certainly. Patients demanding certain treatments that they think someone else is getting and they're not getting, might not be appropriate for them, so I think that would be quite challenging for the care provider to manage. **(HCP-N3)**

Most HCPs felt online health forums were only useful for supportive information. However, they would not recommend this source to patients as there is too much potential for misinformation. They felt they would be more comfortable recommending such a source if the forums were strictly and closely moderated and had the participation of HCPs.

> I do think it does have its place in my profession, but it just it probably needs to be moderated. **(HCP-N9)**

> You've got potential to actually have a really good support network and research if it's moderated by health professionals and it's not just Betty down the road who decided to set a forum up. **(HCP-P6)**

7.4.4.3 Recommending online resources to patients

HCPs had a mixed response when asked, “Do you provide patients with online resources?”. While some encouraged this, others preferred to assess each patient individually to determine their likely ability to access and navigate online health information independently, before making recommendations. For example, HCPs recommended sources in different formats depending on the patient they were seeing. If they felt that the patient was less technologically advanced, they would print out the web source or give them leaflets.

> You can’t tell an 85- or 89-year-old lady, they don’t have the same access and to assume that would be silly. So, you need to have paper copies as well. **(HCP-N9)**

One concern participant’s highlighted was patient’s accessing American websites. Some HCPs believed that many of the results appearing on search engines were Americanised and were usually the first links that would appear on web searches. This was a concern because the services and treatment offered in America, may not be the same in the UK or where the individual is from.

> A lot of information that they google is Americanised websites and America obviously has a very different structure to the NHS and you can’t just pay your way through and demand an MRI at 2 in the morning. We maybe don’t have those facilities and certainly we have to balance on a cost-based model as opposed to just private healthcare, so it works very differently, and I think that the expectations are a lot higher for patients so it’s just managing them. **(HCP-N3)**

Filling information gaps and acknowledging that the patient is most likely to do their own research is important. Therefore, guiding patients to appropriate sources so they are accessing reliable sources can be fundamental to the patient’s understanding of their health situation.

> It’s things like signposting to what’s there when you’re not there. So, you know there are some good patient experiences online, you know there are leaflets available about exercise being safe in heart failure and things like that. So, I think the gaps that you can’t fill in, in the consultation, that’s

> where you have your back-up of web-based resources or leaflets. **(HCP-P7)**

> I think that as health professionals, we play a huge role to guide that information with them. **(HCP-P6)**

7.4.5 The impact of COVID-19

COVID-19 has had an immense impact on HCP's and healthcare systems. This theme relates mostly to the NPT construct reflexive monitoring (appraisal work).

7.4.5.1 COVID-19 online health information

HCPs had mixed perceptions about the distribution of COVID online health information. Some noted that it was as good as it could be as the medical and scientific research was being processed at the same time as it was being delivered.

One doctor discussed that health information had never been more in the spotlight. The COVID-19 pandemic was not only televised and consistently spoken about over various platforms, but it made people to begin to realise the importance of health and other factors that could impact their health such as diet and exercise.

> I think we are seeing more health information in the news than we've ever seen before. **(HCP-D4)**

The differences between the quality of online health information at the beginning of the pandemic in comparison to the current distribution was significant according to one nurse who was deployed to a COVID-19 unit,

> I do think now that we're a year down the line, the online sources have improved, but at the beginning it was kind of very much like no one knew what the difference was between a cough or cold and COVID? So, you would just get everyone rocking up to the hospital because there was no direction on what to do. Whereas now if you Google COVID, you've got signs and symptoms or where to go or when to isolate, whereas we didn't have that at the very beginning. **(HCP-N11)**

Most HCPs felt that although online health information appeared confusing at times, it was as clear and efficient as possible, given the circumstances. However, improvements were suggested that could ease the confusion amongst the public. Examples HCP’s stated that were grey areas in online health information included the use of facemasks, lockdown measures and shielding. Exemplars are provided below when HCP participants were asked their perceptions on the COVID-19 online health information, which demonstrate the mixed perceptions of both confusing and clear information.

> Very conflicting and disjointed, but at the same time, it's understandable because it's the first time in our generation and hopefully our lifetime that we’ll personally live through a global pandemic. And obviously, this information's just evolved, and I think, every second it's changing because we're just finding out new things about it. So, it's understandable as I said, but it’s a bit all over the place. **(HCP-N12)**

> So obviously now we're at a busy stage again. And people are confused again on what to do. So as much as the advice has been good, I can say it could be better. It's also at the same time confusing because we're still in the same position a year later. **(HCP-N11)**

One nurse felt that COVID has influenced many people to do more online research about their health and take more responsibility,

> People that never would have Googled stuff before about health information are doing it more so now. I think because we were all bombarded that we had no choice but to research. Because it affected everyone's life, and day to day life. **(HCP-N5)**

Becoming misinformed from online health information was a reported concern for HCPs. Participants felt that information could easily be misinterpreted or inaccurate which could lead them to make decisions that were not in their best interests. One example provided in the typology below was that people were avoiding healthcare services due to online misinformation,

> If you look at all the chat that’s going on online that you can’t get a GP appointment, no one’s coming out, they’re not doing this, what’s the point in even trying. You’re like, actually, GPs are still working,

> they’re still seeing you, if you need seeing, they will come and see you. **(HCP-P6)**

All Australian HCP participants reported no concerns with the quality of online health information and felt that it was clear and informative.

> I think it’s been great here in Australia. I think everyone knows they can look up anything. There’s lots of contacts on the television and the radio. They are always telling people if you’ve got a cough or any sort of symptoms, get online and google it and find out where your nearest centre is. I think it’s been good. **(HCP-N13)**

> I think it’s been pretty good. I think the government websites for New South Wales health have been good. Just like with the case locations and where hotspots and clusters have popped up, I think it’s been pretty clear. It’s been set out really well so that you can just kind of look on there and see where there have been cases and if you do need to get tested, to just be monitoring for symptoms and things like that. I feel like the information has been quite good. **(HCP-N15)**

7.4.5.2 Everyone is an expert

HCP participants shared that although they are medical professionals, they are also members of the public. They are also people experiencing the same pandemic as everyone else. They reported feeling overwhelmed at times because everyone looked to them for the answers, but everyone was learning at the same time.

> We have guidelines, but a lot of the guidelines just say, there's not enough evidence at the moment to suggest that we should or shouldn't do X. So, it's really difficult for me to then provide advice for other people, but also to take care of myself as a healthcare professional. Should I be looking after people that are COVID positive and also have patients that are COVID negative? Morally, I don't think that's correct, but I'm having to do that. **(HCP-N9)**

> It's a difficult one because our policies and the information we’re getting or the evidence base, is changing at such a fast rate. And the information that the public have, like I'm also a member of the public so the

> information I get is the same as theirs, and I also get information from our management. They're both changing information. So, like the patients may not trust us as much because it's not the same as what they're hearing. Everyone's just suspicious at the moment anyway and it's just not a good dynamic, patient-nurse dynamic. **(HCP-N12)**

HCPs reported that healthcare has never been more opiniated. Everyone is researching, reading and talking about COVID-19, which has led to many people having varied and conflicting opinions.

> Everyone's got something to say at the moment. Everyone's kind of like an expert because they've read this article, which, you know, as we said before, it's a good thing and a bad thing. But it's good to be self-informed. But when the information out there is so vast and as we said, conflicting, it's difficult. **(HCP-N12)**

7.4.5.3 Healthcare services

HCPs reported that online health information has impacted people attending healthcare services and face-to-face appointments. They felt there was a lot of scaremongering happening online which caused many people to not attend services when they needed to. Furthermore, HCP participants felt that people were using the internet for healthcare information more than ever before, and using it as a replacement for healthcare services throughout the pandemic,

> More so than ever I feel like everyone will be just going on the internet and Googling because they're afraid of going out and they're afraid of booking a GP appointment even if it is available to them, they don't want to go. And they're avoiding appointments and things that they should be going to because it's important, like pap smears. **(HCP-N5)**

On the other hand, some HCP participants reported that the online health information regarding accessing healthcare services during the pandemic, could have been improved. People became scared to go to hospital which ended up having a large impact on people's health.

> There was an issue in our department certainly. I was moved back to the ED as a staff nurse and a care provider, and we weren't seeing any patients at all. We had an empty ED that saw up to the realms of 450 patients a day. And people were still having MIs and people were having ECF symptoms but weren't coming in. We were stenting a third less MIs and we were seeing two-thirds less strokes. But these people were still having strokes and MIs. The rate shouldn't have gone down. So, I guess if I was looking at it that way, then it could have been better. Because we scared people so much from coming in that they didn't come in and they sat at home and they were brought in in the back of an ambulance, dead. So, that's kind of a horrifying statistic. So, maybe they put too much emphasis on this 'don't go to hospital', 'do not go out', and then we kind of backtracked and said, 'Oh you need to come to A&E if you're not feeling well'. But that could have maybe been better outlined from the start. **(HCP-N3)**

7.4.6 The impact on relationships

HCP participants were asked, "How do you feel online health information seeking and self-diagnosis has impacted your relationship with patients?" This gathered mixed responses which are divided into three themes, the nurse-patient, the doctor-patient, and the allied HCP-patient relationships. The majority of HCPs within each category of relationship felt that there was an improvement in the relationships as it allowed them to have more informed discussions with patients, and the patients were investing more time into their healthcare. This theme relates mostly to the NPT construct of reflexive monitoring (appraisal work).

7.4.6.1 The nurse-patient relationship

Nurse's views varied on how the phenomenon of online health information has impacted their relationship with patients. Most felt it had positively impacted the relationship, mainly because patients were becoming better informed about their healthcare. However, some felt it had negatively impacted the relationship because they were being challenged and felt some patients wanted to prove them wrong, potentially damaging the relationship.

Some nurses believed when patient's sought information from the internet, they most likely needed reassurance.

> Sometimes all they want is a little bit of reassurance. And that's sometimes all people need is just a little bit of reassurance. And if you already have your guard up, if you're already expecting a bit of a challenge from them as such, I think that ruins the relationship you have. **(HCP-N9)**

Nurse participants felt it was beneficial to gain an insight into patient's information seeking patterns as it allowed them to have a better idea of their concerns.

> Whereas the ones who maybe have done some stuff online beforehand, they're inadvertently telling you what they're worried about by the very nature of what they've looked up. So, I think it can be positive when they come with that because then you're getting an insight into what's worrying them. **(HCP-N7)**

Nurses felt that although patient's seeking health information online can be challenging for them, it can also be a positive challenge to learn more. They appreciated patient's wanting to take responsibility for their health and becoming more involved in their decision making.

> I think probably overall, it's strengthened my relationship with patients because I often find myself getting into really good, informed conversations with patients and I can delve a little deeper than I can with someone who doesn't have any understanding or comprehension of what they're talking about. I think it helps us answer some of the deeper, harder questions that are still just as important but obviously, if people don't really have a great understanding, you're not really going to go deeply into something. I think it's probably strengthened things in that department. **(HCP-N14)**

Most nurses believed the internet helped to achieve a better balance in the relationship.

> It creates more of a balance between the patient-nurse relationship. **(HCP-N12)**

Despite having an overall positive perception, nurses also reported negative perceptions about the impact the internet was having on their relationship with patients. Examples included conflicts of information (when the nurse’s advice is not the same as the patient’s research), feeling challenged by the patient, and the time constraints of having to negotiate the diagnosis with the patient. Some nurses also felt that patients were undermining their expertise when challenging them with their internet findings.

> I would say it makes relationships more difficult from the beginning. And more difficult to get on an even footing or convince the patient that you are the professional, not them. **(HCP-N3)**

Nurses also reported concerns that some patients seemed to have more trust in their online findings than their expertise.

> There have been events where I've been looking after a patient and they’ve just not wanted to listen to what I’ve had to say or what the medical staff have had to say. They're just hell bent on this information that they found out from internet resources themselves. They've done their own research, as they say, all the time. And that can be like a bone of contention, obviously, because as healthcare providers, you're only doing your best. You've got their best interests at heart. You're not trying to trick them or have a ruse over them. So, it's quite sad that patients maybe do feel kind of suspect of healthcare providers, maybe because they've had a bad experience in the past as well. **(HCP-N12)**

One nurse explained that communication could be the key to evolving the nurse-patient relationship. Involving the patient in the decision-making process and ensuring that information is clearly explained to the patient can help reassure them and build trust in the relationship.

> I think part of the reason why it happens as well is because as a healthcare professional and medical professional, we have such a strong evidence base for things. We use and put policies and stringent things that we follow for the reasons we do things, and we know why we're doing it and it just comes as natural. So, we give you this medication because this is going to help X, Y and Z, but sometimes we might not tell the patient that because we don't maybe feel like they'll either understand or maybe the nurse or the doctor doesn't know the lay term to give to a patient for them to understand. So then in that way, there's a communication gap where

> patients then perceive themselves as kind of like a submissive person in the patient healthcare provider relationship and that, ‘oh they don’t want me to know this information. And why would that be? Maybe is it something bad? Should I not know this?’. So, then they'll maybe go and do their own research and look on the internet and I think that’s maybe what it comes out of. Whereas I think maybe if the health care professional was more forthcoming with information when they were providing that care, then they might not do that. **(HCP-N12)**

7.4.6.2 The doctor-patient relationship

All doctor participants reported that patient’s using the internet for health information seeking had a positive impact on the doctor-patient relationship. They felt pleased that patients were becoming better informed and more enthusiastic about forming a partnership and shared decision-making process. They also believed that patient’s becoming more informed helped to balance the doctor-patient relationship, from the paternalistic approach.

> I think it does feel a bit more like there is some balance there and I don’t think its threatening or anything like that. **(HCP-D4)**

Doctors enjoyed working together with patients and felt it improved aspects of their relationships while also encouraging the patient to take more responsibility for their own health. They felt a professional partnership and shared decision-making process was the way forward.

> Normally, there’s a bit of an imbalance right, where we have all the information. Like in the past, doctors would have the information, or healthcare professionals have the information and then we tell it to patients. There are issues, but overall, I’m generally in favour of patients being able to have more information. **(HCP-D4)**

Doctors felt that the internet could be a valuable resource if used correctly and accurate resources are accessed. It can help assist patients in pre- and post-diagnostic information,

> I think if directed to appropriate sources, it can be really, really helpful. The flip side of that being if patients are using sources that are not properly checked or perhaps forums that are maybe less factually correct, it can be dangerous. **(HCP-D2)**

However, concerns were raised that patients may not see doctors in the role they did before as a result of having access to so much health information and felt this could build a barrier in the relationship,

> It has built also another potential barrier to communication because if this whole situation is mishandled then maybe the trust of patients is going to suffer, they're not going to see you the same as before. **(HCP-D1)**

The overall perception from doctor participants was that the internet could be highly advantageous to the doctor-patient relationship and is the future way forward.

> I think that generally it has made it a richer relationship. I think it's a richer relationship because they can bring to me more details, concerns and questions and I can answer them better. And I have a better idea of where their head is at. Also, I can direct them to better resources. So yeah, I think that information re-balance is good. And I think that you know, if they can bring me a sheet of paper of something that they printed off the internet, and I can talk to them about it, and how it relates to them, I actually think they generally respect and trust me even more. And I certainly don't think, I'm not threatened by what they looked up. I think that it actually can be a harness a). for them to have more information, b). for me to clearly communicate to them better and c). for them to understand that they can trust. **(HCP-D4)**

7.4.6.3 The allied healthcare professional-patient relationship

Allied HCPs included two physiotherapists and one physiologist. Their overall perception was positive. They felt that patients participating in healthcare brought better patient outcomes. Allied HCPs also felt it was an opportunity to learn from patients and to find new research they have not yet come across. They also described a partnership and team approach to making health decisions which they felt beneficial as they engaged with the patient more. One physiotherapist explained why,

> I actually really enjoy it. So, I think it's great when people come in and they are citing evidence or they are saying, oh, I read this on the Internet, what do you think about this? And if they've gone having done their own research and then they're asking my opinion on it or my thoughts on it, we can have a very educated conversation and we can kind of go back and forth on why this might not be the best piece of information. So, I think it's definitely a good challenge, not a negative challenge. They're there to challenge me in a way and make me think differently. So, I think it's definitely improved it for the better. **(HCP-P10)**

However, the physiologist participant reported finding the relationship more challenging when patients had premeditated ideas of their healthcare,

> I think it's probably made it more challenging. Because I think people do go to the internet now as their first source and they can kind of see themselves as an expert because they've googled all about the condition. So, I think sometimes it can make the role a bit harder because you need to be patient and provide more education. Rather than people just accepting that education from you as the first source. They sort of already have this other information at the back of their mind so, they're just in a way, just seeing if what you're saying matches up with what they've read online. Rather than taking your word for it. **(HCP-P15)**

Patients having access to online health resources allowed them to build their knowledge on health issues. Allied HCPs felt this was positive and broke down barriers which enabled them to work better with patients,

> It's breaking down that barrier between patient and health professional. Where the doctor knows everything, or health professional knows everything and I'm just a minion at the end of it. It's you giving them that

> information so that actually builds a better relationship with your patients. **(HCP-P6)**
>
> Overall, I think it’s changing for the better. **(HCP-P10)**

7.4.7 Summary: healthcare professional’s perceptions

This chapter explored the perceptions of fifteen HCPs including nurses, doctors and allied HCPs. The overall HCP perception of patients use of the internet for health information was positive. Hesitancies and issues were raised and while there are still many improvements to be made to the accuracy and reliability of online health information, most HCPs saw the advantage of patient’s becoming more invested in their health.

One key point was HCPs found expert patient’s to be valuable to newly diagnosed patients as they had knowledge that HCPs did not have – the lived experience. Therefore, accessing resources such as online health forums could be supportive for someone newly diagnosed with heart failure. However, the majority of HCP participants said they would not recommend online health forums as a resource as there is too much risk of misinformation. They suggested if there were a moderator or the involvement of HCPs in the discussion posts, they would be more trusting towards them.

All HCP participants were in favour of educating and guiding patients to high quality resources. Furthermore, all participants (nurses, doctors and allied-HCPs) were in favour of patients becoming more involved in their healthcare, and forming a professional partnership to make informed healthcare decisions together.

7.4.8 Chapter summary

This chapter has presented the findings of two interview studies, one with members of the public who had experienced the phenomenon of online health information seeking as a user of this information, and the other of HCPs. The themes and subthemes that emerged from the analysis of these interviews were presented as findings. Among both samples, participants were able to identify both positive and negative outcomes from the examined behaviour but overall a realistic and informed picture was portrayed of a phenomenon that is here to stay and become a feature of the changed patient-HCP relationship.

The findings addressed a series of research questions that will be discussed in the context of the existing literature in the next chapter.

Chapter 8 - Discussion

8.1 Introduction

This thesis presents research that comprise a series of related studies. First, a mixed methods systematic review examined public and HCP's perceptions of online health information seeking and how this can impact the patient-HCP relationship, was undertaken and presented in Chapter Five. Second, in Chapter Six, two studies of heart failure online health forums thematically analysed user-posted information, and then the responses posted by peers. The first of these was concerned with the type of information being sought while the second reviewed quality of the feedback/responses provided. Thirdly, Chapter Seven presented the findings of two interview studies investigating the behaviours, perceptions and interpretations of, first, patients and, second, HCPs in regard to online health information seeking. Each component of the overall research was aimed at addressing one or more of the research questions set out in Chapter One.

The aim of this chapter is to discuss the findings of each study and situate them within the existing body of literature, knowledge and understanding of the phenomena of online health information seeking. The chapter also aims to identify where the current research confirms, challenges or extends existing knowledge and to establish its original contributions. The chapter is divided into three main sections. The first synthesises the findings on patient online health information seeking behaviours, the motivations behind them and the benefits and potential problems such behaviours may cause. The second considers the findings related to the use of heart failure online health forums, what they are used for, and the quality of the information exchanged on them. The third section focuses on the consequences of the new widespread behaviour of online health information seeking and the patient-HCP relationship and medical authority in general.

Before discussing the findings in detail, Table 8-1 summarises the main and novel findings related to each research question.

Table 8-1 Main and novel findings related to each research question

Research Question	**Main and novel findings**
RQ1. How does online health information seeking affect the patient-HCP relationship and medical authority?	- Rise of the active patient who wishes to interact from an informed position. - Effect on the relationship largely determined by how the HCP responds to a patient introducing online information. - Allowing patients to communicate health information obtained online and responding positively can positively affect the relationship.
RQ2. How do HCPs perceive patients use of online health information and its effect on the patient-HCP relationship?	- HCPs perceptions were mixed but mostly positive. - Some HCPs felt challenged and less trusted. - HCPs reluctant to contradict online information for fear of adversely affecting the relationship. - Some HCPs felt their expertise was being challenged but they did not feel personally intimidated. - Overall HCPs saw online health information seeking as a positive process and one that can help to improve the patient-HCP relationship.
RQ3. How do public/patients perceive the use of online health information and its effect on the patient-HCP relationship?	- Some view it as complimentary to the relationship. - Self-management and self-diagnosis of symptoms or conditions seen as a help not hindrance. - Knowledge gap filling, investigating terminology, and preparing for HCP appointments were highlighted. - Discussing online research was seen as improving the relationship when HCP responded positively. - Negative HCP reactions could cause distrust and embarrassment. - No intention to challenge HCP, just to be better prepared.
RQ4. How does online health information seeking shape people's decision-making?	- Online health forums were a tool to support decision making and improve understanding of diagnosis and treatment.

	- Lack of insurance coverage forced some people to use online health forums as a decision-making tool. - Many use online health forums to inform decision making regarding whether they should seek further medical attention, change medication or to inform lifestyle choices.
RQ5. What information do people concerned about heart failure seek when using online health forums for self-diagnosis?	- Information to address unanswered questions due to lack of time in consultations. - Life expectancy of patients diagnosed with heart failure, medications, lifestyle, diet, exercise, health insurance queries as well as symptoms of heart failure. - People access such forums to gain support and have their concerns legitimised. - People are seeking support for their mental health as they feel they are not just experiencing physical symptoms.
RQ6. How does the use of online health forums, in the context of heart failure, affect people's trust in HCPs?	- Some forum users may undergo confirmation bias as using the forums confirms their negative perceptions of HCPs regarding misdiagnosis or insufficient appointment time. - People using online health forums may be posting mostly negative experiences.
RQ7. How evidence based is the diagnostic advice provided from heart failure online health forums and what are the types of information responses provided on them?	- Online health forum content not a reliable source of high-quality evidence-based information on diagnosis of heart failure and some information is dangerous. - Online health forums are mostly a supportive resource as opposed to a reliable diagnostic source.
RQ8. What are the public and HCP perceptions of online health forums and	- Online health forums for heart failure offer significant negatives (poor quality information) and equally significant positives (support).

social media support groups as an information source?	- Online health forums seemed more helpful to people who were diagnosed with heart failure or had long-term conditions. - HCP's felt online health forums could be useful for support but would not personally recommend this source to a patient due to the potential for misinformation. However, they would assess this on an individual basis.
RQ9. How has the availability of online health information influenced the patient-HCP relationship?	- A substantial change in the relationship is underway. - Online health forums can gather a collection of peers with similar negative experiences which can promote distrust with HCPs. - HCPs reported difficulties finding time to discuss online health information findings during already short appointments.
RQ10. What are the perceptions of online health information surrounding COVID-19 and the impact of such information among healthcare services?	- Scarcity and shortness of appointments, intensified during pandemic, and may have driven increased online health information seeking. - Phenomenon became less elective and more mainstream. - Online health forums used to discuss issues such as shielding and to seek clarification of what was sometimes confusing official advice. - Danger of information overload recognised among those shielding at home.

8.2 NPT as an explanatory framework

The discussion takes for its explanatory framework the NPT, first introduced in Chapter One. To recap, NPT offers a conceptual framework that contributes to the understanding of how patient online self-diagnosis and health information seeking can impact the patient-HCP relationship and help facilitate the implications and changes to practice. As May et al. (2014) describe,

> NPT supports the analysis of nursing work by focusing on the ways that clinical nursing practice is made coherent and meaningful, how it leads to sets of relational commitments, how these contributions are enacted and contextualized, and how they are appraised and reconfigured. (p. 298)

The four elements of NPT, first presented in Chapter 3, are shown in Figure 8-1 with the main elements of the phenomenon of online health information seeking mapped onto them.

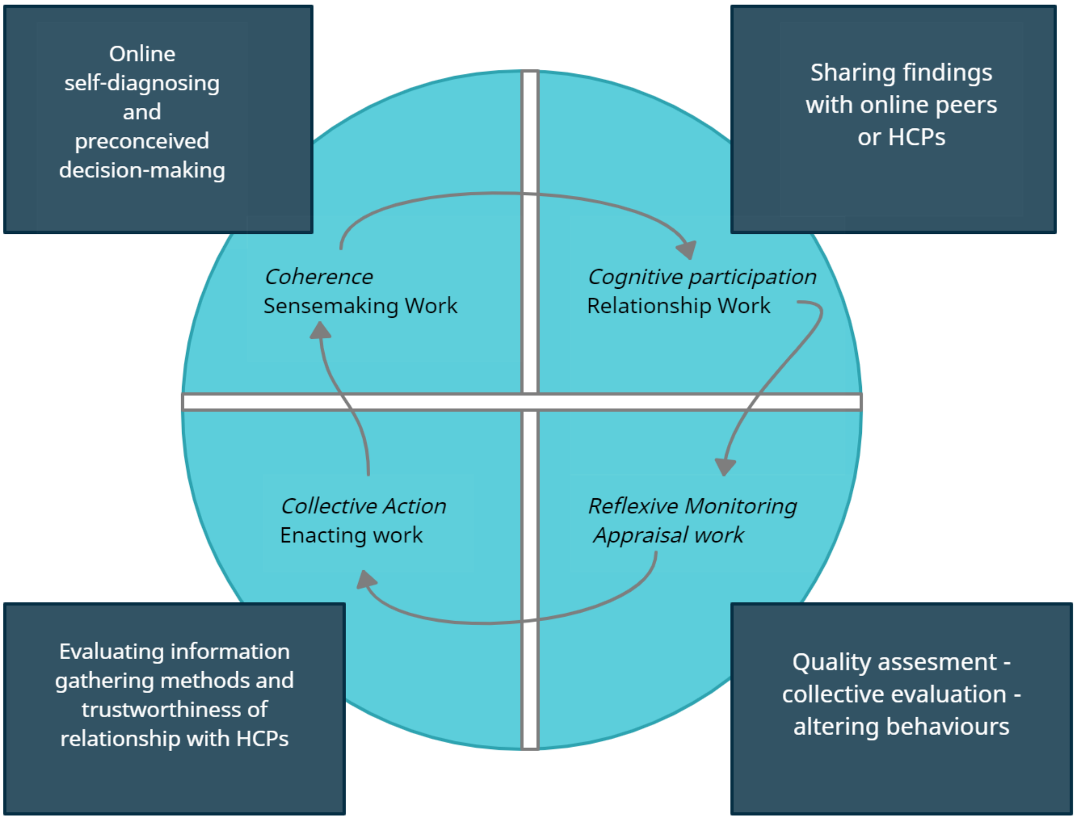


Figure 8-1: The main elements of online health information seeking

NPT was developed as an explanatory tool to explain new ways of thinking, acting and organising work in healthcare settings (May et al., 2009) and has also been used to help understand the work of self-management (treatment burden) (Gallacher et al., 2011). It is particularly aimed at addressing three central problems. Firstly, the way new practices are brought to implementation through social organisation. Secondly, how this implementation develops into routine incorporation into the day-to-day work of groups and/or individuals (embedding). And third, how newly embedded practices become self-sustainable and self-reproducing within the social matrices of the organisation (May et al., 2009). It is posited that ‘things’ do not become embedded without the actions of actors making NPT essentially a theory of action. As the name suggests, it is also a theory of normalisation used to explain how something new, such as a new technology moves from this newness onto normalcy. It is therefore appropriate for use in the present study. Understanding the processes of implementation, embedding and integration of the internet into the work of self-diagnosis, therefore requires an understanding of the motivations, beliefs, perceptions, actions and values of the actors concerned, which is the approach taken in this research.

8.3 Patient motivations for online health information seeking

Online health information seeking is often triggered by a specific health concern. Participants reported resorting to searching the internet driven by concerns and even fears about their health and therefore this behaviour is often undertaken while experiencing certain negative emotions. While anxiety and fear were found to be a motivating factor of encouraging online health information seeking pre-diagnosis, the result of such behaviour may be anxiety-reducing among those already having a diagnosis. Boot and Mejiman (2010) postulated that patients may seek the same reassurance they desire from their HCP, from their information-seeking behaviour, describing it as a “ritual soothing procedure” (p. 152). Similarly, Minto et al. (2015) found that cardiomyopathy patients reported reduced anxiety when information-seeking, suggesting the behaviour may have a therapeutic value. The degree of therapeutic value and anxiety reduction may depend on the patient’s perception of the quality of the information found and their self-efficacy in interpreting the information (Silver, 2015). In line with the existing literature, the present study confirms the existence of an emotional and mental health dimension to health information seeking behaviours.

The internet has made previously hard to find information, available to the general public, including health information. The accessibility of online health information was identified by study participants as being a key advantage. The significance of accessibility has also been identified in the literature (Donnelly et al., 2008; Stevenson et al., 2007; Macias & McMillan, 2014). In addition to the generally accessible nature of the internet, patients have compared the availability of HCPs negatively to the 24/7 online option. A person concerned about a symptom late in the evening may turn to the internet because there is no access to a HCP (Fiksdal et al., 2014). Furthermore, internet accessed information could be revisited as frequently as required and at no cost (Rupert et al., 2014). Not only is access easy, it is also available at any time of the day or week which earlier studies have found is valued, particularly in the case of online health forums (Coulson et al., 2007; Chung, 2014; Johnston et al., 2013; Plinsinga et al., 2019). The present study also found that accessibility is linked to reassurance that participants highlighted as an associated advantage. Generally, the status of accessibility was confirmed as a key advantage and motivation to use the internet to seek health information.

In contrast to the indications that online health information and access to online health forums had a reassuring effect, and possibly some therapeutic value, there is a counterbalancing cautiousness rising to possible anxiety among some, related to information-seeking. Both patients and HCPs in the present study referred to concerns related to mental health. This finding resonates with previous research as earlier studies have found that curiosity often led people to use online resources, but the potential output of negative information and possibility of misinterpreting information led to anxiety (Bell et al., 2011; Boot & Mejiman, 2010). On the positive side, online groups offer informational, emotional, and network support (Coulson et al., 2007). Furthermore, this support was available in an anonymous, judgement-free environment in which patients felt more comfortable sharing their experiences. The present study confirmed that seekers of information online were capable of exercising caution; however, this finding cannot be generalised to all people and negative effects on mental health such as anxiety remains a concern.

While accessibility of the internet plays an important role in motivating patients to seek health information online, the perceived inaccessibility of HCPs has an equal effect. Participants reported using the internet due to having to wait for an appointment, or not being able to get one at all due to the high demand for healthcare services. Furthermore, participants reported using the internet while waiting for future appointments or for surgery they were on a waiting list for (Donnelly et al, 2008). Other studies have reported that any perceptions of barriers between patient and HCP is likely to stimulate online health information seeking (Fiksdal et al, 2014), a finding also confirmed by the present study. Use of the internet for health information is a phenomenon that has coincided with growing pressures on HCPs time that is reflected directly in the length of time allocated to each appointment. GP appointments in the UK are among the shortest in Europe at around nine minutes per patient (The Pharmaceutical Journal, 2017) which, based on this and other studies, may drive online health information seeking behaviours. Short appointments had numerous relevant consequences in this study. Patients felt they were not given enough time to ask questions surrounding a diagnosis such as lifestyle, diet and mental health impact. This was one of the most prevalent reasons people accessed online sources after the HCP consultation and is in line with other literature (Bowes et al., 2012; Donnelly et al., 2008).

Relatedly, the nature and performance of a country's healthcare system may influence online health information seeking behaviour. The present study included participants from contrasting types of health systems – taxpayer funded, free at the point of use (UK, NHS) and the insurance-based system of the US. American participants reported issues and complexities with health insurance policies. If contacting or making appointments with a HCP had a direct cost consequence, patients may turn to online health information as a free alternative. Fiksdal et al. (2014) noted a similar inclination among US study participants. In the UK, concern about the performance of the NHS was also found relevant to patients for whom concerns appeared to undermine the status of medical authority with patients sensing they were on a more equal footing than earlier generations (Donnelly et al., 2008).

Sometimes healthcare appointments do not completely fulfil a patient's information requirements, perhaps due to the time limitations placed upon them. Participants in the present study reported using the internet to plug these gaps. One specific need identified in the study was to fully understand terminology used at the appointments, with heart patients reporting some terms were hard to understand. This resonates with work by Cajita et al. (2017) who also found terminology issues among heart patients upon receiving initial diagnosis. Later health literacy improved, partly due to online health information seeking. Participants in this study voiced similar experiences. Additionally, a novel finding from participants in this study was the lack of recognition for the emotional and mental health impact that comes with heart failure and long-term conditions. Participants reported feeling unprepared for the impact on their mental health that came with the diagnosis and felt they were not given sufficient resources or guidance on this.

The availability of health information online is associated with the rise of the active patient. Many participants in the present study could be classed as active patients based on their responses. Based on the study findings, the active patient is characterised by a sense of ownership of their own health, a desire to seek out new evidence regarding their particular condition and saw it as important and beneficial to interact with HCPs from an informed position. The active patient views interactions as a dialogue. This contrasts with earlier manifestations of the relationship in which medical authority was the source of medical knowledge. These findings have support within the literature. Donnelly et al. (2008) reported that while patients use the internet to consolidate a perceived more even level of knowledge, they stop short of feeling there is no longer a need to see HCPs. Although, in the UK, HCPs are the gatekeepers to treatment and so are needed for prescriptions and referrals. These changed perceptions of medical authority are driving a “fundamental and important” change in the patient-HCP relationship (Townsend et al., 2015). The present study adds to our understanding of the nature of the active patient and confirms the evidence that a substantial change in the relationship is underway.

While there are undoubtedly changes underway in the patient-HCP relationship, not all online information seekers perceive their own behaviours as undermining that relationship. The current research found that some participants saw these behaviours as more complimentary than conflicting. The emotional support and the benefits of self-management and self-diagnosis of symptoms or conditions were seen as non-conflicting with the relationship. Bowes et al. (2012) also identified this perception with patients viewing their seeking of health information online as helping both themselves and the HCP make the most of the short time allocated for the appointment. They used it to focus the mind of the HCP and avoid receiving a disinterested reaction. In the present study, the use of online information was part of the preparation for an appointment and part of being an active patient which was overwhelmingly viewed as positive.

The study found that the online health information seeking phenomenon had spread beyond the GP surgery and was familiar to nursing professionals. Younger nurses and those with a more academic background seem well equipped to meet the challenge presented by internet-informed patients. The nurses in this study viewed this phenomenon mainly in a positive light with an indication they recognised that it may encourage them to stay up to date with the information on offer.

To summarise, as discussed above there are many motivational factors for seeking health information online. Knowledge gap filling, investigating terminology, and preparing for HCP appointments all featured strongly. While health system factors can influence these behaviours, patients do not necessarily see their behaviours as damaging to the patient-HCP relationship. Scarcity and shortness of appointments may be driving online health information seeking. It can be speculated that this may have intensified during the COVID-19 pandemic as access to healthcare was restricted further. Information is sought to prepare for the appointment and to clarify and investigate what was said at them. In regard to the existing literature, the present study was mainly confirmatory and in line with the evidence base. Patients seem aware of both the upsides and downsides of this behaviour in terms of mental health and emotional wellbeing. Condition-specific forums that are available constantly and anonymously seem to have a significant role to play. In the following section this role is discussed further in specific regard to those affected by heart failure.

8.4 The use of heart failure online health forums

This research included two studies of the use of heart failure online health forms. One was a thematic analysis of posts made by patient users of such forums and another a thematic analysis of the peer-to-peer responses to such posts. The findings of these studies were presented in Chapter Six. For discussion purposes, these findings are synthesised and interpreted within the context of the existing literature to identify where the findings confirm, contradict or develop the existing knowledge base. The first study aimed to understand how patients used these forums and what kind of information was sought on them. The second evaluated the quality of the information being shared. The studies yield a number of novel findings and significant contributions to knowledge.

First presented in Chapter One, the research questions related to the use of heart failure online health forums enquired about the nature of the information sought on such forums and the effect of this information on decision making. The perceptions of both public and HCPs on the use of these forums, and the effect of such use on trust in HCPs. They also addressed the nature and quality of the responses made to online forum posts.

The ubiquitous nature of online health forums and peer-to-peer communication, and the continued expansion of online resources suggest the use of such resources is likely to gain increasing importance for HCPs. Online health forums allow peers to connect globally. They generate relational content which enables individuals to share their own experiences within the confines of the forum (Jeong et al., 2018; Y. Lu et al., 2013; Sudau et al., 2014; Willis, 2014). However, online health forums also represent an opportunity to provide misinformation and this study found 10% of the information provided was unsafe and not evidence based. Nonetheless, such forums provide support, addressing issues of isolation and ensure users feel they are not alone (Cole et al., 2016; Mamykina et al., 2015; Sarrazin et al., 2014).

From the first study it could be seen that forum users had a range of different reasons for using online health forums. While some wanted an opportunity to discuss results, others sought information variously about the life expectancy of patients diagnosed with heart failure, medications, lifestyle, diet, exercise, health insurance queries as well as symptoms of heart failure. Online health forums served as a tool to support the decision-making process and to improve understanding of diagnosis, treatment, results or other information provided by HCPs. There was some evidence that these forums may promote distrust in HCPs.

Previous research has examined how online health forums satisfy patients' needs (Attard and Coulson, 2012; Ziebland & Wyke, 2012), and the findings resonate with that earlier work in relation to how people use online health forums to gain support and address gaps in understanding and knowledge (Li et al., 2014). This tended to be additional information seeking alongside HCP consultations as users felt they had unanswered questions due to lack of time in consultations. The prominence of peer-to-peer and informational support described here is consistent with previous research (Coulson et al, 2007; Coursaris & Liu, 2009). Similarly, to Bell et al (2011), we found that discussions centre on medications, lifestyle factors (diet and exercise), as well as the impact their diagnosis or symptoms could have on their lifestyle.

The seeking of health information from online health forums is well documented and the evidence suggests that users benefit from this information (Grosberg et al., 2016; Green et al, 2014). While previous research has predominately focused on the supportive elements of online health forums (Kaufman & Whitehead, 2018; Deetjen & Powell, 2016; Moore & Ayers, 2017), this study found that not only do users use online health forums for supportive aspects, but also to fill informational gaps that are not addressed by HCPs.

Several of the factors identified, resonated with previous online health forum studies. Online health forums clearly provide and signpost helpful and supportive information to users (Cole et al., 2016; Mamykina et al., 2015; Sarrazin et al., 2014). Online health forums shared more than just diagnostic responses. They provided an opportunity to connect with peers around the world, to share experiences, and to build a supportive community which has been noted previously (Jeong et al., 2018; Lu et al., 2013; Sudau et al., 2014; Willis, 2014). The findings suggest that for most people, the internet is used to complement, rather than replace offline sources, which is consistent with other research (Tan & Goonawardene, 2017; Thorne et al., 2004). Several concerns such as the potential for misinformation and conflict between peers, have been discussed in previous literature (Plinsinga et al., 2019). Furthermore, the anonymity of online health forums can introduce the increased likelihood of receiving hostile comments and misinterpretation due to the constraints of non-verbal communication (Coulson et al., 2007; Plinsinga et al., 2019).

Interestingly, responders rarely signposted users to consult nurses; rather they usually suggested visiting the doctor, GP or cardiologist. Traditionally, primary HCPs were GPs. However, the nursing profession is expanding, and nurses are taking on more advanced and extended roles. Advanced nurse practitioners, primary care nurses and specialist nurses are becoming more common, and this will continue to increase with time. It is expected for patients to increasingly refer to nurses on online health forums as the profession grows (Wilson et al., 2020). Previous literature has suggested that HCPs should improve their awareness about online health information and communities, so they have greater knowledge of the types of informal social support networks patients are engaging with (Tan & Goonawardene, 2017).

Importantly, this research shows that HCPs and healthcare systems are still not adequately meeting the healthcare information needs of people with possible or confirmed heart failure (Browne et al., 2014) and that online health forums serve an important role in supporting such individuals. This suggests greater emphasis should be placed on providing HCPs with support, and the systems and resources to better address the healthcare information needs of people with heart failure, including access to reliable online health resources.

Nurses and other HCPs need further support and training to learn more about patients use of online health forums to gain a better understanding about the types of information patients seek and to consider how best to address such knowledge deficits. Healthcare systems should be aiming to ensure sufficient time and resources are available to meet patient information needs.

As discussed, many of the findings of the present research were confirmatory regarding the existing empirical knowledge of the phenomenon of use of online health forums. However, this research also uncovered several significant novel findings. Firstly, with patients often drawn to seeking health information on online health forums through a negative perception or experience with a HCP, such as a belief that appointments are too short or even that diagnoses are mistaken, they may undergo confirmation bias in a way that amplifies their initial beliefs. The research suggests that many people go to online health forums when they are unhappy with their healthcare; feel insufficiently supported; or feel information from

HCPs is unclear or inadequate. Online health forums can gather a collection of peers with similar negative experiences which can promote distrust with HCPs.

Another novel finding is that lack of insurance coverage forced some people to use online health forums as a decision-making tool. Additionally, many use online health forums to inform decision making regarding whether they should seek further medical attention, change medication or to inform lifestyle choices.

The study contributes new insight on the reliability and overall quality of information posted on online health forums for heart failure. This content could not be considered a reliable source of high-quality evidence-based information on diagnosis of heart failure, with only eleven percent of the responses including comprehensive or partial evidence, and ten percent of responses being non-evidence-based and potentially dangerous.

However, the presented findings go further and suggest that gaining a diagnosis or having symptoms is only part of the reason people use such forums, and that people access such forums to gain support and have their concerns legitimised. In NPT terms, this can be viewed as cognitive participation work. The forums provide a community of support and experiential connectivity, which appears to be the key benefits of online health forums for those with heart failure. Hence, we can conclude that in the case of online health forums for heart failure, there are significant negatives (poor quality information) and equally significant positives (support).

In summary, online health information seeking often takes place in the context of HCP appointments, either as appointment preparation or post-appointment investigations. The behaviour has the potential to both cause and relieve anxiety depending on quality of information, and an individual’s health literacy determining their ability to interpret the information. Online health forums may be particularly supportive, though HCPs may need to advise patients on how to best use them. This may be challenging for HCPs as their time with patients is already limited.

8.5 Implications of online health information seeking for the patient-healthcare professional relationship

The first research question asked, *How does online health information seeking affect the patient-HCP relationship and medical authority?* By conducting interviews with people from both sides of this relationship it was possible to construct a triangulated response to this question by synthesising the perceptions and interpretations of both patients and HCPs.

It was clear from the findings that patients felt they had a better relationship with their HCP when they were able to discuss their online research with them and when their HCP responded positively to this. While, if people perceived a negative reaction from the HCP, this could cause distrust and embarrassment. HCPs felt that if they disagree with information that the patient highly values, this may adversely affect the patient-HCP relationship. Similar perceptions have been noted in other studies (Stevenson et al., 2007; Sommerhalder et al., 2009).

The findings also demonstrate that allowing patients to communicate health information obtained online with their HCP in the consultation, as well as the HCP showing that they value the patients' research, can positively affect the relationship between the two. When HCPs create an atmosphere that is open, this can encourage patients to discuss the information they have discovered. Additionally, the patient's perception of invading the role of the HCP or their embarrassment may be reduced, which, overall, can enhance the relationship between the patient and HCP. These findings are in line with and confirm earlier literature (Ahluwalia et al., 2010; Townsend et al., 2015).

Firstly, as mapped in the NPT framework, the findings suggest that online health information empowers the patient and influences them to participate further in their healthcare (Bartlett & Coulson, 2011; Benetoli et al., 2018). However, while this was empowering, the HCP profession still remained important due the medical expert knowledge. It was most commonly found that people would use the internet as a decision-making tool that assisted them pre and post diagnosis. For more serious concerns, all public participants preferred the expertise of a HCP instead of the internet. However, most still used the internet to understand the management and treatment process, or to find other people who are sharing similar experiences to them.

HCP's reactions to people who had obtained health-related information from the internet were mixed; however, they were mostly positive. Some HCPs felt that it was good that patients were looking after their own health, whereas others felt they were being challenged with information found online and that their patient had lost trust in them when they turned to the internet for help. Some also thought it could cause anxiety among patients – especially when the information was misinterpreted, and this could lead to unnecessary medical visits (Ahluwalia et al., 2010; Caiata-Zufferey & Schulz, 2012). HCP behavioural and communication responses were a highly important attribute in determining whether the consultation would be a positive or negative experience for the internet-informed patient, ultimately impacting the overall output of the patient-HCP relationship. If the HCP was dismissive of the patient’s research, this usually caused embarrassment and discomfort, and led to distrust towards the HCP (Townsend et al., 2015). If the HCP responded positively and was open to communicating with them about their internet findings, patient’s felt comforted and listened to, and felt they trusted the HCP more when they were able to be included in the information and decision-making process.

From the HCP perception, while there was a mixed response, all HCPs agreed upon the benefits of patient empowerment encouraging them to take better care of their health which resonated with previous research (Barnoy et al., 2008; Barnoy et al., 2011; Caiata-Zufferey et al., 2012). They also felt that it allowed them to have more informative conversations in the consultation as long as the patient approached the consultation in a way that was willing to work with the HCP, instead of becoming confrontational with information. All HCPs were happy to work with patients in a professional partnership however, some questioned whether patients began to undermine their years of education, training and expertise due to the patient self-research process.

Combining both public and HCP perceptions, it can be concluded that both share the same outcome of wanting to work together in a professional manner to achieve the best care for the patient. While patient empowerment is a key advantage of health information seeking, it comes with the importance of acknowledging expert knowledge by HCPs. Patient empowerment and self-diagnosis do not make the patient a medical professional. These findings resonate with a possible limitation in patient empowerment (Cullen, 2008) and the importance of medical expert knowledge in determining the balance in the relationship (Broom, 2005).

The impact of online health information on the patient-HCP relationship can signify both an opportunity and a challenge. All identified opportunities and challenges imply a more empowered patient. The main challenges are raised for the HCP who may have to interpret misleading findings to the patient, which may cause time to be lost in the already limited timeframe they have, an issue which is particularly problematic in resource constrained healthcare systems. The data suggests that the danger of the HCP feeling offended or intimidated by a more informed patient is of little relevance, which contradicts findings in the existing literature (Donnelly et al., 2008, Ahluwalia et al., 2010; Bowes et al., 2012; Caitata-Zufferey & Schulz, 2012). While it is true that HCPs reported feeling challenged in the present study, this challenge was to their expertise and fell short of intimidation in the opinion of HCP participants.

The significance of the online information impact on the relationship is mainly determined by the information's quality, the types of resources and the patient's evaluation of the internet (Silver 2015; Wang et al., 2018). Presuming the information is high quality and accurate and appropriate evaluation of the information by the patient, the benefits for the patient-HCP relationship dominate. However, if the patient accesses low quality resources and misinterprets information, this can cause strain on the patient-HCP relationship, mainly due to healthcare system issues such as time constraints. This leads to HCPs having to spend time correcting the patient's beliefs about their diagnosis or providing alternative diagnoses and having to convince patients that the HCP diagnosis is correct and the internet one is not. The patient evaluation of online health information appears to be more important than anticipated.

As quality of information and its evaluation by patients are unpredictable, the argument that the HCP must stay important due to their medical expertise, knowledge and experience is supported. If the patient evaluation and interpretation of the online health information is limited, the patient's empowerment is too.

However, individuals may not always know their evaluation capabilities are limited. Patients can be led to believe their self-diagnosis is correct and the information they found online provides them with enough medical knowledge to arrive at a diagnosis, which again causes difficulties when HCP's have to spend time (some might think wasting time), during a time constrained consultation, explaining why a different diagnosis is more appropriate (Wang et al., 2018). A consistent link has been found within the findings – 1) patient self-diagnosis and premeditated decision-making; 2) patient interpreting findings and sharing information with HCPs; 3) HCPs addressing the patient findings and either having an informed discussion or re-interpreting the information to the misinformed patient; 4) reflecting on the time constraints in the healthcare system; and 5) reflecting on a management process which helps when having appointments with internet-informed patients.

While patient empowerment represents as a potential advantage of patient's use of the internet, the findings show that even if HCPs are not always the first resource people access, their medical expertise and experience of clinical decision-making, put them in the most trusted position to make medical decisions. However, the findings from this study have shown while this is true, the relationship has evolved from paternalistic to a partnership approach. Therefore, this study found consistencies within the patient and HCP perceptions to be in favour of the evolution of a professional partnership and shared decision-making process.

Patients found HCPs to be the most valued source of health information but found the internet to be a useful complementary tool (Donnelly et al., 2008; Hay et al., 2008; Sommerhalder et al., 2009; Caiata-Zufferey et al., 2010; Mendes et al., 2017). Although evidence has previously found that the internet can potentially have a negative impact on the patient-HCP relationship and can cause barriers in the relationship (Caiata-Zufferey & Schulz, 2010), this study has suggested that patients' use of the internet for self-diagnosis and health research has the potential to positively impact the patient-HCP relationship.

All public participants reported they did not use the internet to challenge the HCP, but instead to be prepared for their consultations and what's to come. Being more informed allowed people to feel more secure and better equipped when attending healthcare appointments. It also allowed them to prepare appropriate questions and give themselves a better understanding in advance of consultations.

The nurse, doctor and allied HCP perceptions all shared similarities in responses. Nurses presented arguments that they felt patient's online health information seeking behaviours allowed them to have insights into the patient's true concerns and worries and felt patients who had such behaviours needed the most reassurance. Overall, nurses felt challenged at times but not intimidated. Nurses suggested they felt challenged by patients who placed greater weight on their internet findings than on nursing expertise. However, they mostly felt positive that the patient was taking such steps to take responsibility for their own health, and they would provide reassuring care to all internet-informed patients.

Doctors mostly felt enthusiastic about patient's presenting with internet findings, as long as it was with an approach that was not confrontational. They reported that patient's self-research behaviours brought balance to the relationship and recognised these changes were superseding the paternalistic approaches that have traditionally been more common in the doctor-patient relationship. However, doctors reported that they would make an assessment on an individual basis of how to deliver responses in consultations. For example, some patients may only want to know necessary information and have more preference for the paternalistic approach, while others may want to form partnerships. Doctors reported feeling enthusiastic with both situations but were overall supportive of patient empowerment.

Allied HCPs (physiotherapists and physiologist) reported feeling positive about patient's online health information seeking. They mostly reported that even if what the patient has found is wrong, all they had to do was explain why it was wrong and then put them on the correct pathway. Therefore, it was not a burden, it was a positive process. Allied HCPs frequently reported the benefits of providing patient education but also being able to learn from patients. When patients brought research that they had not come across, this was a learning opportunity and they felt this helped their professional development.

Overall, the public and HCPs in this study shared similar perceptions which emphasised that both groups wanted the same outcomes, they may just have different approaches. While HCPs were still cautious about patient's online health information seeking, they felt it was a positive process and one that can help to improve the patient-HCP relationship. More informed patients allow for more informed discussions which leads to a shared decision-making process and in turn, creates a professional partnership.

8.6 The COVID-19 pandemic and online health information seeking

The COVID-19 pandemic emerged during the course of this research. As the most serious pandemic to emerge during the internet age, it represented a unique opportunity to explore the phenomenon of online health information seeking. The role of social media and the traditional mass media interest in academic studies that would normally attract little if any public attention has been unprecedented. It was, therefore, appropriate to add a further research question to the current research which sought to understand the way public and HCPs perceived impact of COVID-related online health information.

Whereas use of the internet for health information seeking had previously been an elective behaviour carried out alongside access to formal healthcare services, the pandemic and the tight restrictions on access to healthcare settings meant that now the online option for information became firmly mainstream. Participants voiced concern over this lack of access to HCPs and their reliance on online information. In the case of those living with cardiac conditions, the anxiety caused by the pandemic was intensified by their status as more vulnerable to serious disease resulting from infection. Online health forums were used to discuss issues such as shielding and to seek clarification of what was sometimes confusing official advice. Participants also recognised that they may experience information overload by spending too much time accessing pandemic-related information online which could lead to confusion rather than clarity.

In this study, HCPs recognised how online health information seeking and the ongoing issues it raises were intensified during the pandemic. More people were drawn to the behaviour for the first time. Also, the presence of poor-quality information and even deliberate misinformation was a particular concern. While the subsample was small (n=4), Australian HCPs had a more positive view of the quality of online information. Despite the availability of information online, the public still turned to HCPs for information on COVID-19. However, with a rapidly changing situation and a novel virus, evidence-based answers were not always available. Similarly, an analysis of search engine results showed that most of the information provided online was sub-optimal with quality, usability, readability, and reliability issues (Jayasinghe et al., 2020).

The potential for confusion found in the present study has been echoed elsewhere in the literature. The global nature of the pandemic is reflected in global research interest. Tang and Zou (2021) noted both a reasonable level of satisfaction with online information but also reported information fatigue, in their Chinese study. Among a digitally literate sample of German students, concerns were raised about the reliability of online information, the difficulty in determining whether there was a commercial motivation behind the information as well as finding the specific information they were interested in (Dadaczynski et al., 2021). Earlier in this chapter, online health information seeking was associated both with increased anxiety and in some cases, the receiving of support from online health forums for anxiety relief. According to Shabahang et al. (2020), this association is replicated in the specific case of COVID-19 and consumption of COVID-19 related news disseminated online, which was a significant predictor of COVID-related anxiety among Iranian students. Furthermore, the quality concerns raised by the HCP participants in the present study have been echoed elsewhere such as in a Spanish study (Hernández-García & Giménez-Júlvez, 2020). Tran et al. (2020) examined the quality issue but from the Vietnamese HCP and community workers perspective. Their analysis concluded that the pandemic had highlighted the need for online channels aimed at these HCP key workers to be strengthened as existing dissemination was inadequate for meeting these information needs. In a rapidly evolving pandemic, literature should be viewed in the context of what stage of the pandemic the data was collected in, and the particular circumstances of the setting. As the pandemic progressed, much attention switched to the vaccine and to conspiracy theories related to it and other aspects of the pandemic (Abbasi, 2021).

The present study adds qualitative understanding to the scholarly response to the COVID-19 pandemic and its association with the already-established phenomenon of online health information seeking. Most other studies have used samples of the general public or of HCPs, but although the present research added COVID-19 related data collection, once the work had already been operationalised, it represents a rare example of a study considering both public and HCP perspectives. In some ways, the COVID-19 pandemic can be viewed as bringing the issues addressed by this research into sharp focus. The public have been estranged from their HCPs in ways not seen in normal times. With internet connectivity levels now very high, certainly in developed countries, online information seeking has filled this gap and exposed its strengths and weaknesses.

To summarise, the COVID-19 pandemic has created an environment which has accelerated online health information seeking. Access to HCPs has been restricted and, in many cases, people have found themselves working from home or furloughed with extra time and opportunity to search online. Then there are the concerns with the virus itself and the demand for information on the pandemics progress, diagnosis, vaccine news and government restrictions. As a new and unfolding situation, the pandemic has been a case study in the role of online health information seeking in national health systems.

8.7 Chapter summary

The scope of the research questions and the multi-study research design adopted for the research means that a triangulated examination of the research problem could be undertaken. It encompassed the online provision of health information in general as well as the specific subtype of heart failure online health forums. It triangulated data sources by conducting online semi-structured interviews including the perceptions and interpretations of the general public (both diagnosed and undiagnosed) and HCPs. It added to these, a systematic review of literature on online health information seeking and a thematic analysis of posts made on heart failure online health forums and responses to these posts. The result is a rich picture of the current impact of this phenomenon on the provision of healthcare and, in particular, on the patient-HCP relationship. The following chapter summarises the contributions made by this research and the implications they have for practice and for future research.

Chapter 9 - Conclusions and Implications

9.1 Introduction

As in most countries, the status of medical authority and the significance of a family's relationship to HCPs, particularly the GP, was markedly high. The country's health institutions such as the UK, are an important part of the fabric of society, indeed part of the national identity. The arrival of the internet and the way it transformed access to information has had deep repercussions for these fundamentals of social organisation. The research presented in this thesis set out to provide a broad and rich picture of how online health information seeking is perceived by both patients and HCPs and how the relationship between them is being affected. It built this investigation on a thorough review of what is already known, aiming to contribute empirically, theoretically and methodologically to the field. This chapter presents these contributions before moving on to the strengths and the limitations of the research. To fulfil the practical objectives of the study, the chapter proposes a series of recommendations, first for further research, second for practice, and third for policy. The thesis is then completed with some closing remarks.

9.2 Research contributions

Researchers aim to make original contributions to empirical knowledge, theory and research practice. By opting for a broad and triangulated research design combining multiple studies of the same phenomenon, it was intended to not only fill knowledge gaps but also to broaden knowledge of the phenomenon of online health information seeking. Additionally, the research adopted NPT as an explanatory framework and in doing so, makes a theoretical contribution by providing a further test and example of its utility addressing a research problem it has yet been used for. Finally, research can make important methodological contributions in both the design and the operationalising of the investigation. The present study can claim to offer researchers an innovative triangulated design providing thoroughness and breadth to the examination of the phenomenon. Contributions at each of the three levels are now considered in more detail.

9.2.1 Empirical contributions

An empirical contribution is “a novel account of an empirical phenomenon that challenges existing assumptions about the world or reveals something previously undocumented” (Ågerfalk, 2019, p. 594). The insights into peer focused resources such as online health forums and perceptions of the public and HCPs, can be used to contribute towards clinical practice and policy in order to improve the patient-HCP relationship in the context of internet health. This involves recommendations for HCPs in their approach and understanding of internet-informed patients; a knowledge of the use of online health forums and if this is considered a source that can be recommended to patients; and future practices of working with internet-informed patients in professional partnerships and shared decision-making processes. Some factors that could be directly implemented are adapting behavioural and communicative approaches which can help reduce patient confusion that influences self-research and reduces the potential of misinformation.

In comparison to earlier work on patient online health information seeking, the work described in this thesis focused on the evolution of the patient-HCP relationship by gathering patient/public and HCP’s perceptions, and data on the quality of online health forums for heart failure, as a popular peer resource. Combining these findings have provided valuable insights regarding the impact of online health information seeking behaviours on the patient-HCP relationship but also provided new information about the quality of resources people are using. No previous studies have combined such studies to make recommendations. However, some findings from this thesis does resonate with earlier work as outlined in Chapter Eight.

Key themes relating to support, accessibility, mental health, preparing for appointments and seeking reassurance have been found by others (Chung, 2014; Plinsinga et al., 2019; Jeong et al., 2018; Boot & Mejiman, 2010; Tan & Goonawardene, 2017). Interpretation of online health information is the concept that has been least examined by other research and one of the key findings within this research. One important finding in this thesis that resonates with the work of others is that many people are drawn to the internet as a means of support and to take part in an online community setting. It has become a place where people can share their concerns with one another, without the fear of judgement and with the option of staying anonymous.

None of the studies mentioned above or throughout this thesis have looked at the quality of evidence provided on heart failure online health forums. However, several studies have explored online health forums for general use and the role they play in supporting patients. Although these studies were not aimed at exploring heart failure specifically, many findings resonate highly with the work described in this thesis regarding online health forums and communities, such as using such sources to gain reassurance and find support from other peers.

The present study also confirmed that rather than being a phenomenon restricted to the GP-patient relationship, the issues related to online health information seeking are relevant to all HCPs. Nurses are equally aware of the phenomenon and encounter it routinely in their relationships with patients. While some felt challenged, most nurses seem able to respond positively when a patient raises their internet obtained information, which is important as the study suggests that this positive response helps maintain a good relationship.

9.2.2 Theoretical contributions

This research makes a theoretical contribution by advancing our understanding of the NPT framework and its related concepts. The use of NPT as the underpinning theoretical framework for this thesis has been a key strength of this research. It provided a significant foundation on which to analyse and interpret the findings from the mixed methods systematic review (Chapter 5) and the data Chapters 6 and 7. This provided scope to compare and contrast the findings from the data collected in the mixed method systematic review in Chapter 5. The iterative mapping of the themes identified against the NPT framework, aided reflection and understanding of the key concepts identified and has helped to shape the recommendations being outlined in this chapter. NPT is well documented to be a theory of implementation that is appropriate to utilise to answer the types of questions posed in this thesis and in addition, has also been used increasingly to help conceptualise the work of self-management by patients and their carers (Gallacher et al., 2011; Gallacher et al., 2013). Using NPT helped to describe and explain processes identified through analysis of the data collection throughout the duration of this PhD. Using this theoretical lens to reflect upon the data has helped to explain the key issues more clearly. Strengths of using NPT throughout this thesis were that it helped to provide a level of consistency in the analysis and mapping process. Furthermore, the use of NPT helped to maintain a consistent approach throughout the lifecycle of this thesis from informing the planning phases and interview guides, through to analysis and evaluation. Application of

NPT to what is potentially the most significant new phenomenon in recent times, carries with it substantial usefulness in terms of future research in this field.

9.2.3 Methodological contributions

This thesis was approached from a critical realist stance, which allows the truth to be regarded as a 'regulative ideal' while at the same time, accepting that it is impossible to have certainty that such truths have been attained. These beliefs resonate well to the collection of evidence from different sources that aid our understanding of patients use of the internet for self-diagnosis and health information seeking. This triangulation of methods has resulted in a broader and deeper understanding as well as increasing the credibility of the results.

The approach to data collection assembled a diverse range of views from online health forums where individuals felt free to comment and engage in discussions unbounded by the formal constraints of the research environment, and with the protection of anonymity. This meant that the study could be based on an analysis of honest, publicly offered guidance, views, perceptions, and interactions concerning different heart failure conditions and scenarios. Another advantage of this method is its resource effectiveness and the fact that it facilitates access to large quantities of data in a relatively short amount of time.

Recruiting nurses, doctors, physiotherapists and a physiologist strengthened this study as it brought insight from a multi-disciplinary team, making this the first study to collect perceptions from multiple different healthcare professions in the context of patient online health information seeking. Many previous studies have focused on the patient perspective alone. However, this study brought findings that proposed similarities and comparisons of the public and HCP perspectives, and also the similarities and differences in the professions of the HCP perceptions.

HCPs in the interview study were initially recruited on the basis of having experienced patients who self-diagnosed or searched for online information on heart failure. It quickly became apparent the specificity and difficulty of HCPs to recall specific experiences unless they were cardiac specialised. Therefore, an ethics amendment was submitted and accepted to recruit HCPs based on their experiences with internet-informed patients. A mix of cardiac specialist HCPs and HCPs from other disciplines were recruited. This concluded the results to be richer as few previous studies have focused on the HCP perspective, as most have focused on the patient’s perspective of using of the internet for health information.

Despite the growing use of online health forums, very little research makes use of this low-cost resource for identifying people’s health interests to guide person-orientated research. Additionally, this information could be used to help us better understand patient support needs, to underpin a more person-centred healthcare delivery. HCPs and health care systems should use learning from such forums to identify service gaps and care deficiencies to optimise care delivery. For the publishers of online health forums, the findings indicate that increased benefits may accrue through the addition of a moderator to monitor the accuracy of information, minimise the dissemination of misinformation and to stamp out or at least reduce negative behaviours.

9.3 Limitations of the research

There were several limitations related to the operationalisation of the research. One related to the systematic review presented in Chapter Five. Unlike clinical type studies, where each condition or intervention has one universally used term, there is no consistently used terminology to describe the patient-HCP relationship and the aspects related to it. Only English language articles were searched for, which may have reduced the number of potentially relevant studies. Secondly, sources of information such as conference proceedings, theses and abstracts and grey literature were not included, which means some related studies may have been missed.

Two qualitative descriptive studies were conducted to analyse heart failure online health forums. This type of study was undertaken as no previous research was found prior to this study, and it is important to develop an understanding for the research to be explored further. There are several limitations to this study. Analysis was based upon posts specifically about heart failure in publicly available online health forums, within a limited timeframe (2016-19). Selecting another time frame for analysis may have yielded different health conversations and using a different subject matter may have elicited different types of responses. Nonetheless, this study is novel and was underpinned by the robust conceptual framework, NPT. However, as the discussion forum respondents remained anonymous it was impossible to obtain complete information in respect of the demographic characteristics of the sample. The scale of the study was limited to online health forums discussing heart failure. Online health forums for different conditions could have yielded different results.

However, while the characteristics of the sample inevitably remain ambiguous, the ability of this method to harvest spontaneous views is indisputable.

As with many interview studies, there were limitations on sample and subsample size. Qualitative studies do not seek to achieve larger representative samples from which results can be generalised to other populations. Rather, insights are developed through looking at issues in-depth (Kelly, 2010). The interview analysis presented in this thesis is based upon responses from 31 individuals. This represents a smaller sample size in relation to the population from which it was drawn, and caution must be taken when transferring these findings to the wider population. Furthermore, social media was used to recruit for this study. Therefore, the public/patient sample may be more digitally able and with higher literacy. Additionally, HCP's who use the internet more often may have responded. Therefore, the patient's/public and HCP's who responded, may have been better informed and more positive about this subject area than the wider populations of HCP's and patients. Further research could explore on a larger scale, the transferability of these findings to a wider population.

9.4 Recommendations

The practice and implementation of the phenomenon of patient's use of the internet for self-diagnosis and health information seeking can be improved by implementing a number of changes and adaptations to the HCP work setting. The implications and recommendations for the current study revolve around the level of research, practice, policymaking and management of healthcare systems.

9.4.1 For research

- There is a lack of research including the nursing perspective. As the nursing profession expands and more roles continue to develop such as the advanced nurse practitioner and heart failure nurse specialist, it is essential to follow the impact of online health information seeking on relationships between patients and nurses. Future research should explore this as the role continues to expand, particularly the impact on specialist nurses. Technology and the nursing profession will continue to grow and there will be more contact between internet-informed patients and primary care or specialist nurses.

- Future research should have a focus on the role of patient evaluation and sense-making of online information. This would gather insight into how patients are interpreting distributed online health information.
- Assessing the benefits/risks of moderated forums, which have the potential to reduce the spread of misinformation (McGregor et al., 2014) versus unmoderated would be beneficial. Moderators can be useful to online health forums as they can monitor posts and ensure the forums are being used appropriately, and the distributed information is accurate. Therefore, it would be useful to further explore whether the users of online health forums are more likely to contribute with or without a moderator, and the differences in the quality of health forums with or without a moderator.
- Future research could examine a broader range of online health forums and consider direct interaction with users to gain their perspectives. Further work should explicitly examine whether online health forums do promote distrust in HCPs, and if so, how best to address this issue.

9.4.2 For practice

- Online health forums are used by many people as a decision-making tool to help inform steps within their healthcare pathway. It will be important for nurses and other HCPs to discuss use of such resources during consultations to ensure a clearer understanding of current patient knowledge and beliefs.
- This work suggests knowledge deficits remain an important challenge for people with heart failure. This suggests that HCP's and healthcare systems need to consider methods (e.g., to enhance patient understanding of the condition), need to provide more support (e.g., considering information needs around the diagnosis such as lifestyle changes) and resources (signposting to reliable online resources), to better address the healthcare information needs of people with heart failure. Furthermore, guiding people with heart failure to appropriate sources that may help them address their needs safely after the appointment.
- People use online health forums to connect with others sharing similar experiences. Health care systems should consider hosting such forums to provide support but also to ensure the information provided is reliable.
- HCPs should discuss using resources such as online health forums with patients and explain the benefits and risks of using them, while assessing the patient appropriately to know whether this would be an appropriate resource for them to

use. For example, if the patient was diagnosed with heart failure and was seeking support, online health forums may be useful to them, and the HCP could assess whether they feel this resource would help the patient and recommend appropriately.

- Online health forums may amplify distrust with HCPs, and it will be important to acknowledge this may be an issue that needs addressed within consultations.
- There is a need to provide more education and training to nurses and HCPs about the types of information patients are accessing out with appointments. This should become integrated in the training curriculum of HCP's.
- HCP communicative and behavioural approaches are suggested within the findings of this thesis for the implementation for future practice with internet-informed patients. Such approaches have been found to help patients engage in better discussion with the HCP. For example, people reported feeling more comfortable to share their internet findings, when they feel their HCP is open to discussion and listens to their findings.

9.4.3 For policy makers and management of healthcare systems

- To consider addressing the time constraints within healthcare systems for HCPs, to enable them to discuss any concerns or issues with patients in-depth. Additionally, more time provided in consultations would benefit explanatory work to aid patient understanding and allow for checking the extent of understanding. For example, providing more time for people with heart failure, particularly those who are newly diagnosed, and consider their information needs may stem beyond diagnostic information.
- Introducing a new role such as trained patient partners or peers who could act as an extension of the HCP role to help people better understand their condition. This could also help with the time constraints as it provides another information resource in addition to the HCP.
- To provide education and training for HCPs, perhaps beginning with online training modules, on the development of internet-informed patient's and guides on what types of resources to recommend. Furthermore, nurses and other HCPs need further support and training to learn more about patients use of online health forums to gain

a better understanding about the types of information patients seek and to consider how best to address such knowledge deficits.

9.5 Closing remarks

This study was motivated by experiences from both my nursing practice and my own personal life. This motivation was further strengthened by my early readings on the topic which marked online health information seeking out as an area of importance, interest, and relevance. Some of the coverage of the online phenomenon I had read before embarking on this research suggested that the patient-HCP relationship could be seriously undermined by internet-informed patients and call into question medical authority that had dominated this relationship for centuries, and certainly since the establishment of the NHS. As I worked through the phases of the research, a different picture emerged. While some people would use their internet-obtained information in a way that may leave the HCP feeling challenged or less trusted, the majority are acting in an entirely reasonable and rational way. In the digital age, it is natural and predictable that one of the uses of the internet is the seeking of medical information, such as diagnostic and treatment information. With appointment time a limited resource, patients go online both before and after appointments to better understand their diagnoses and treatments. Instead of the defensiveness that one might intuitively expect from HCPs, there was a significant degree of understanding for the patients' motivation. Younger members of the nursing profession who grew up and were trained in the digital age as well as those with greater self-epistemic authority, seem in a particularly strong position to respond positively to the phenomenon. However, more research is needed, particularly in view of the expansion of the nursing profession and the increasing need to understand the nurse-patient relationship.

This research also shed light on the dilemma presented by online health forums. The dilemma is how to benefit from the positive support function these forums undoubtedly offer while mitigating the risks from the poor quality, non evidence-based information they contain. This issue too requires further investigation.

Finally, the phenomenon of online health information seeking is here to stay. The trend is almost certainly to increase in prevalence. The nursing and other healthcare professions need to fully recognise this, embrace it and include it in their education and professional development programmes.

References

Abbasi, J., 2021. COVID-19 conspiracies and beyond: how physicians can deal with patients' misinformation. *JAMA*, *325*(3), pp.208-210.

Adams, W., 2015. Conducting Semi-Structured Interviews in Newcomer, K. E., Hatry, H. P., & Wholey, J. S. Handbook of practical program evaluation, 492.

Ågerfalk, Pär J., 2014. Insufficient theoretical contribution: a conclusive rationale for rejection? pp.593-599.

AHA. (2017). Diagnosing Heart Failure. Available at: https://www.heart.org/en/health-topics/heart-failure/diagnosing-heart-failure (accessed 23 September 2020)

Ahluwalia S., Murray E., Stevenson F., Kerr C., Burns J., 2010. 'A heartbeat moment': qualitative study of GP views of patients bringing health information from the internet to a consultation. *60*(571) pp. 88-94.

Ajzen, I., 2011. The theory of planned behaviour: Reactions and reflections.

Al-Ajlan, A., 2015. The comparison between forward and backward chaining. International *Journal of Machine Learning and Computing, 5*(2), p.106.

American Psychological Association (APA) 2020. Conducting research during the COVID-19 pandemic. Available at: https://www.apa.org/news/apa/2020/03/conducting-research-covid-19 (accessed 20th July 2020).

Apple, 2007. *Apple Reinvents the Phone with iPhone*. Available from: https://www.apple.com/uk/newsroom/2007/01/09Apple-Reinvents-the-Phone-with-iPhone/ (accessed 20 September 2020)

Archibald, M.M., Ambagtsheer, R.C., Casey, M.G. and Lawless, M., 2019. Using zoom videoconferencing for qualitative data collection: perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods*, 18, p.1609406919874596.

Atkins, S., Lewin, S., Ringsberg, K.C. and Thorson, A., 2011. Provider experiences of the implementation of a new tuberculosis treatment programme: a qualitative study using the normalisation process model. *BMC Health Services Research*, *11*(1), pp.1-12.

Atkinson, M., 2011. Interpretivism. In *SAGE key Concepts: Key concepts in sport and exercise research methods* (pp. 117-120). London: SAGE Publications Ltd

Attard, A. and Coulson, N.S., 2012. A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behavior*, *28*(2), pp.500-506.

Audrain-Pontevia, A.F. and Menvielle, L., 2018. Do online health communities enhance patient-physician relationship? An assessment of the impact of social support and patient empowerment. *Health services management research*, *31*(3), pp.154-162.

Austin, Z. and Sutton, J., 2014. Qualitative research: Getting started. *The Canadian journal of hospital pharmacy*, *67*(6), p.436.

Ayling, R. and Mewse, A.J., 2009. Evaluating internet interviews with gay men. *Qualitative health research*, *19*(4), pp.566-576.

Balls, P., 2009. Phenomenology in nursing research: methodology, interviewing and transcribing. *Nursing times*, *105*(32-33), 30-33.

Band, R., Bradbury, K., Morton, K., May, C., Michie, S., Mair, F.S., Murray, E., McManus, R.J., Little, P. and Yardley, L., 2017. Intervention planning for a digital intervention for self-management of hypertension: a theory-, evidence-and person-based approach. *Implementation Science*, *12*(1), pp.1-13.

Banos Díez, J.E., 2007. How thick the shield should be: Teaching the subtleties of the doctor-patient relationship using literature and popular movies. *J Med Mov, 3*(4), pp.159-165.

Barnoy, S., Volfin-Pruss, D., Ehrenfeld, M. and Kushnir, T., 2008. Factors affecting nurses' attitudes in Israel toward patients who present them with Internet medical information. Nursing outlook, *56*(6), pp.314-321.

Barnoy, S., Volfin-Pruss, D., Ehrenfeld, M. and Kushnir, T., 2011. Self-epistemic authority and nurses' reactions to medical information that is retrieved from Internet sites of different credibility. Nursing & health sciences, *13*(3), pp.366-370.

Bartlett, Y.K. and Coulson, N.S., 2011. An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. *Patient education and counseling, 83*(1), pp.113-119.

Batterham, P.J., 2014. Recruitment of mental health survey participants using Internet advertising: content, characteristics and cost effectiveness. International journal of methods in psychiatric research, *23*(2), pp.184-191.

Bell, R.A., Hu, X., Orrange, S.E. and Kravitz, R.L., 2011. Lingering questions and doubts: online information-seeking of support forum members following their medical visits. *Patient education and counseling, 85*(3), pp.525-528.

Benetoli A, Chen T, Aslani P., 2018. How patients' use of social media impacts their interactions with healthcare professionals. *J Patient education counselling. 101*(3): pp.439-44.

Benigeri, M. and Pluye, P., 2003. Shortcomings of health information on the Internet. *Health promotion international*, *18*(4), pp.381-386.

Berg, C.J., Buller, D.B., Schauer, G.L., Windle, M., Stratton, E. and Kegler, M.C., 2015. Rules regarding marijuana and its use in personal residences: findings from marijuana users and nonusers recruited through social media. Journal of environmental and public health.

Best, P., Gil-Rodriguez, E., Manktelow, R., & Taylor, B. J., 2016. Seeking Help from Everyone and No-One. *Qualitative Health Research, 26*(8), pp. 1067-1077

Bhaskar, R.A., 1997 [1975], *A Realist Theory of Science*, London: Verso.

Bhaskar, R.A., 1998 [1979], *The Possibility of Naturalism* (3rd edition), London: Routledge

BHF. (2020). Information & Support. Available at: https://www.bhf.org.uk/informationsupport (accessed 20 September 2020).

Bickley, M.S., Kousha, K. and Thelwall, M., 2020. Can the impact of grey literature be assessed? An investigation of UK government publications cited by articles and books. *Scientometrics, 125*(2), pp.1425-1444.

Blickem, C., Kennedy, A., Jariwala, P., Morris, R., Bowen, R., Vassilev, I., Brooks, H., Blakeman, T. and Rogers, A., 2014. Aligning everyday life priorities with people's self-management support networks: an exploration of the work and implementation of a needs-led telephone support system. *BMC health services research, 14*(1), pp.1-12.

Bodie, G.D. and Dutta, M.J., 2008. Understanding health literacy for strategic health marketing: eHealth literacy, health disparities, and the digital divide. *Health marketing quarterly, 25*(1-2), pp.175-203.

Bogden, R.C. and Biklen, S.K., 1982. *Qualitative research for education: An introduction to theory and methods.* Boston: Allyn and Bacon Inc.

Boot, C.R. and Meijman, F.J., 2010. The public and the Internet: Multifaceted drives for seeking health information. *Health Informatics Journal, 16*(2), pp.145-156.

Boudon, R. 1991 What middle-range theories are. pp. 519-522.

Bowes, P., Stevenson, F., Ahluwalia, S. and Murray, E., 2012. 'I need her to be a doctor': patients' experiences of presenting health information from the internet in GP consultations. British Journal of General Practice, 62(604), pp.e732-e738.

Bradbury-Jones, C., 2007. Enhancing rigour in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of advanced nursing*, *59*(3), pp.290-298.
Bradshaw, C., Atkinson, S. and Doody, O., 2017. Employing a qualitative description approach in health care research. *Global qualitative nursing research, 4,* p.2333393617742282.

Braun, V. & Clarke, V. 2013. *Successful Qualitative Research*, London, Sage.

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*. *3*(2), pp.77-101.

Braun, V. and Clarke, V., 2012. Thematic Analysis. *APA Handbook of Research Methods in Psychology 2* (2), pp.57–71.

Braun, V., & Clarke, V., 2014. What can "thematic analysis" offer health and wellbeing researchers? *International journal of qualitative studies on health and well-being,* 9(1)

Braun, V., & Clarke, V. (2021). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*. Advance online publication.

Breines, M., Cin, M., Sachikonye, M., Madge, C. and Long, D., 2021. Transnational online research: recognizing multiple contexts in Skype-to-phone interviews. *Qualitative Research*.

Broom, A., 2005. Medical specialists' accounts of the impact of the Internet on the doctor/patient relationship. *Health 9*(3), pp.319-338.

Brown, R.J., Skelly, N. and Chew-Graham, C.A., 2020. Online health research and health anxiety: A systematic review and conceptual integration. *Clinical psychology: Science and practice, 27*(2), p.e12299.

Browne S, Macdonald S, May CR, et al., 2014. Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *Plos one 9*: e93288.

Bryman, A. (2012) *Social Research Methods* Oxford: Oxford University Press

Bryman, A., 2008. Why do researchers integrate/combine/mesh/blend/mix/merge/fuse quantitative and qualitative research. *Advances in mixed methods research, 21*(8), pp.87-100.

Bryman, A., 2017. Quantitative and qualitative research: further reflections on their integration. In *Mixing Methods: Qualitative and quantitative research* (pp.57-78). Routledge.

Burbary, K., 2011. Facebook demographics revisited-2011 statistics. Available at: https://www.socialmediatoday.com/content/facebook-demographics-revisited-2011-statistics (accessed October 11 2020)

Burgess., R. 2002. In the field: and introduction to field research, London, Routledge.

Burls, A., 2014. What is critical appraisal?. Hayward Medical Communications.

Bygstad, B., Munkvold, B. E., & Volkoff, O., 2016. Identifying generative mechanisms through affordances: A framework for critical realist data analysis. *Journal of Information Technology, 31(*1), pp.83–96.

Bylund, C.L., Gueguen, J.A., Sabee, C.M., Imes, R.S., Li, Y. and Sanford, A.A., 2007. Provider–patient dialogue about Internet health information: an exploration of strategies to improve the provider–patient relationship. Patient education and counseling, 66(3), pp.346-352.

Byng R., Norman I. & Redfern S., 2005. Using realistic evaluation to evaluate a practice-level intervention to improve primary health care for patients with long-term mental illness. *Evaluation, 11*(1), pp. 69–93

Caiata-Zufferey M, Schulz PJ., 2012. Physicians' Communicative Strategies in Interacting With Internet-Informed Patients: Results From a Qualitative Study. *Health Communication. 27*(8) pp. 738-49.

Caiata-Zufferey, M., Abraham, A., Sommerhalder, K. and Schulz, P.J., 2010. Online health information seeking in the context of the medical consultation in Switzerland. *Qualitative health research, 20*(8), pp.1050-1061.

Cajita, M.I., Rodney, T., Xu, J., Hladek, M. and Han, H.R., 2017. Quality and health literacy demand of online heart failure information. *The Journal of cardiovascular nursing*, *32*(2), p.156.

Carbonell, X., Chamarro, A., Oberst, U., Rodrigo, B. and Prades, M., 2018. Problematic use of the internet and smartphones in university students: 2006–2017. *International journal of environmental research and public health*, *15*(3), p.475.

Chris, A., 2019. *Top 10 Search Engines in The World.* [online] reliablesoft.net. Available at: https://www.reliablesoft.net/top-10-search-engines-in-the-world/ (Accessed December. 1, 2019).

Chu JL, Snider CE., 2013. Use of a social networking web site for recruiting Canadian youth for medical research. *J Adolesc Health 52*(6) pp.792-794

Chu, J. T., Wang, M. P., Shen, C., Viswanath, K., Lam, T. H., & Chan, S. S. C., 2017. How, when and why people seek health information online: qualitative study in Hong Kong. *Interactive journal of medical research, 6*(2), e24.

Chung, J.E., 2014. Social networking in online support groups for health: how online social networking benefits patients. *Journal of health communication*, *19*(6), pp.639-659.

Cline, R. J. W. K. M. Haynes; Consumer health information seeking on the Internet: the state of the art, Health Education Research, Volume 16, Issue 6, 1 December 2001, Pages 671–692

Cole, J., Watkins, C., & Kleine, D. (2016). Health advice from internet discussion forums: how bad is dangerous? Journal of medical Internet research, 18(1), e4.

Collins, C.S. and Stockton, C.M., 2018. The central role of theory in qualitative research. *International Journal of Qualitative Methods, 17*(1), p.1609406918797475.

Comulada, W.S., Step, M., Fletcher, J.B., Tanner, A.E., Dowshen, N.L., Arayasirikul, S., Baker, K.K., Zuniga, J., Swendeman, D., Medich, M. and Kao, U.H., 2020. Predictors of Internet Health Information–Seeking Behaviors Among Young Adults Living With HIV Across the United States: Longitudinal Observational Study. *Journal of Medical Internet Research*, *22*(11), p.e18309.

Corry, M., Porter, S., & McKenna, H., 2019. The redundancy of positivism as a paradigm for nursing research. *Nursing Philosophy*, *20*(1), e12230.

Coulson, N.S., Buchanan, H. and Aubeeluck, A., 2007. Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient education and counseling*, *68*(2), pp.173-178.

Coursaris CK and Liu M., 2009. An analysis of social support exchanges in online HIV/AIDS self-help groups. *Computers in Human Behavior 25* pp. 911-918.

Creswell, J. W. 2013. *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*, London, Sage.

Creswell, J., 1994. *Research Design: Qualitative and quantitative approaches* Thousand Oaks, CA: Sage

Creswell, J.W., 2015. Revisiting mixed methods and advancing scientific practices. *The Oxford handbook of multimethod and mixed methods research inquiry*.

Crichton, S., & Kinash, S., 2003. Virtual ethnography: Interactive interviewing online as method. *Canadian Journal of Learning and Technology/La revue canadienne de l'apprentissage et de la technologie*, *29*(2).

Critical Appraisal Skills Programme, CASP, 2018. *10 questions to help you make sense of a qualitative research.* [online] Available at: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf [accessed 4th March 2020].

Cullen, R., 2008. Empowering patients through health information literacy training (Vol. 131, pp. 49-65).

Curasi, C. F., 2001. A Critical Exploration of Face-to Face Interviewing vs. Computer-Mediated Interviewing. *International Journal of Market Research*, *43*(4), 1-13.

Dadaczynski, K., Okan, O., Messer, M., Leung, A.Y., Rosário, R., Darlington, E. and Rathmann, K., 2021. Digital Health Literacy and Web-Based Information-Seeking Behaviors of University Students in Germany During the COVID-19 Pandemic: Cross-sectional Survey Study. *Journal of Medical Internet Research*, *23*(1), p.e24097.

Dahl, S. and Eagle, L., 2016. Empowering or misleading? Online health information provision challenges. *Marketing intelligence & planning*. 34(7), pp. 1000-1020.

Dang, D., and Dearholt, S.L., 2017. *John Hopkins Nursing Evidence-Based Practice: Model and Guidelines*. Sigma Theta Tau.
Darvishpour, A., Vajari, S.M. and Noroozi, S., 2018. Can health belief model predict breast cancer screening behaviors?. *Open access Macedonian journal of medical sciences*, *6*(5), p.949.

Davidoff, F., Dixon-Woods, M., Leviton, L. and Michie, S., 2015. Demystifying theory and its use in improvement. *BMJ quality & safety*, *24*(3), pp.228-238.

Deakin, H., & Wakefield, K., 2014. Skype interviewing: Reflections of two PhD researchers. *Qualitative Research, 14*(5), 603-616.

Deetjen U. and Powell J.A., 2016. Informational and emotional elements in online support groups: a Bayesian approach to large-scale content analysis. *Journal of the American Medical Informatics Association 23*: pp. 508-513.

Denzin, N.K., 2012. Triangulation 2.0. *Journal of mixed methods research, 6(*2), pp.80-88.

Department of Health and Social Care (2020). *The NHS Choice Framework: What Choices are Available to me in the NHS*. Available from: https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs. (accessed October 2 2020).

Dharamsi, S., & Scott, I. (2009). Quantitative and qualitative research: received and interpretivist views of science. *Canadian family physician Medecin de famille canadien, 55*(8), pp. 843–844.

Dickinson, C., Gibson, G., Gotts, Z., Stobbart, L. and Robinson, L., 2017. Cognitive stimulation therapy in dementia care: exploring the views and experiences of service providers on the barriers and facilitators to implementation in practice using Normalization Process Theory. *International psychogeriatrics, 29*(11), pp.1869-1878.

Diefenbach, T., 2009. Are case studies more than sophisticated storytelling?: Methodological problems of qualitative empirical research mainly based on semi-structured interviews. *Quality & Quantity*, *43*(6), pp.875-894.

Dikomitis, L., Green, T. and Macleod, U., 2015. Embedding electronic decision-support tools for suspected cancer in primary care: a qualitative study of GPs' experiences. Primary health care research & development, 16(6), pp.548-555.

Donnelly, L.S., Shaw, R.L. and van den Akker, O.B., 2008. eHealth as a challenge to 'expert' power: a focus group study of internet use for health information and management. *Journal of the Royal Society of Medicine, 101*(10), pp.501-506.

Eastin, M.S., 2001. Credibility assessments of online health information: The effects of source expertise and knowledge of content. *Journal of Computer-Mediated Communication, 6*(4), p.JCMC643.

El Sherif, R., Pluye, P., Thoër, C. and Rodriguez, C., 2018. Reducing negative outcomes of online consumer health information: qualitative interpretive study with clinicians, librarians, and consumers. *Journal of medical Internet research*, *20*(5), p.e9326.

Endnote. EndNote | Clarivate Analytics 2018. Available from: https://endnote.com/. (accessed March 2 2021)

Eysenbach, G. and Kohler, C., 2002. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *Bmj, 324*(7337), pp.573-577.

Farnood, A., Johnston, B. & Mair, F.S., 2020. A mixed methods systematic review of the effects of patient online self-diagnosing in the 'smart-phone society' on the healthcare professional-patient relationship and medical authority. *BMC Med Inform Decis Mak* 20, 253.

Farnood, A., Johnston, B. and Mair, F.S., 2021. An analysis of the diagnostic accuracy and peer-to-peer health information provided on online health forums for heart failure. *Journal of Advanced Nursing*.

Farnood, A., Johnston, B. and Mair, F.S., 2021. Understanding the use of heart failure online health forums: a qualitative study. *European Journal of Cardiovascular Nursing.*

Fenner, Y., Garland, S.M., Moore, E.E., Jayasinghe, Y., Fletcher, A., Tabrizi, S.N., Gunasekaran, B. and Wark, J.D., 2012. Web-based recruiting for health research using a social networking site: an exploratory study. *Journal of medical Internet research, 14*(1), p.e20.

Fiksdal AS, Kumbamu A, Jadhav AS, Cocos C, Nelsen LA, Pathak J, et al., 2014. Evaluating the process of online health information searching: a qualitative approach to exploring consumer perspectives. *Journal of medical Internet research*. *16*(10):e224-e.

Finch, T.L., Mair, F.S., O'Donnell, C., Murray, E. and May, C.R., 2012. From theory to'measurement'in complex interventions: methodological lessons from the development of an e-health normalisation instrument. *BMC medical research methodology*, *12*(1), pp.1-16.

Flinders University (2010) AACODS Checklist Available at: https://dspace.flinders.edu.au/jspui/bitstream/2328/3326/4/AACODS_Checklist.pdf (accessed January 16 2021).

Fox, S. and Chesla, C., 2008. Living with chronic illness: A phenomenological study of the health effects of the patient-provider relationship. *Journal of the American Academy of Nurse Practitioners*, *20*(3), pp.109-117.

Fox, S. and Duggan, M., 2013. Health online 2013. *Health* pp.1-55.

Franx, G., Oud, M., De Lange, J., Wensing, M. and Grol, R., 2012. Implementing a stepped-care approach in primary care: results of a qualitative study. *Implementation Science*, *7*(1), pp.1-13.

Fritz, R.L. and Vandermause, R., 2018. Data collection via in-depth email interviewing: Lessons from the field. *Qualitative Health Research*, *28*(10), pp.1640-1649.

Fylan, F., 2004. Semi-Structured Interviewing in Marks, D. F., & Yardley, L. *Research methods for clinical and health psychology*. London: SAGE Publications

Gallacher, K., May, C.R., Montori, V.M. and Mair, F.S., 2011. Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *The Annals of Family Medicine*, *9*(3), pp.235-243.

Gallacher, K., Morrison, D., Jani, B., Macdonald, S., May, C.R., Montori, V.M., Erwin, P.J., Batty, G.D., Eton, D.T., Langhorne, P. and Mair, F.S., 2013. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS medicine*, *10*(6), p.e1001473.

Garner, P., Hopewell, S., Chandler, J., MacLehose, H., Akl, E.A., Beyene, J., Chang, S., Churchill, R., Dearness, K., Guyatt, G. and Lefebvre, C., 2016. When and how to update systematic reviews: consensus and checklist. *bmj*, *354*.

Giveon, S., Yaphe, J., Hekselman, I., Mahamid, S. and Hermoni, D., 2009. The e-patient: a survey of Israeli primary care physicians' responses to patients' use of online information during the consultation. *Isr Med Assoc J*, *11*(9), pp.537-541.

Glynos, J. & Howarth, D.R., 2007. *Logics of critical explanation in social and political theory*, Routledge, London

Graffigna, G., Barello, S., Bonanomi, A. and Riva, G., 2017. Factors affecting patients' online health information-seeking behaviours: The role of the Patient Health Engagement (PHE) Model. *Patient education and counseling*, *100*(10), pp.1918-1927.

Gray, L.M., Wong-Wylie, G., Rempel, G.R. and Cook, K., 2020. Expanding qualitative research interviewing strategies: Zoom video communications. (5), pp.1292-1301.

Green RA, Farchione D, Hughes DL, et al., 2014. Participation in asynchronous online discussion forums does improve student learning of gross anatomy. *Anatomical sciences education* 7 pp. 71-76.

Grey Net International, 2020. *Grey Literature Network Service 2021*. Available from: http://www.greynet.org/home.html. (accessed February 12 2021).

Grosberg D, Grinvald H, Reuveni H, et al., 2016. Frequent surfing on social health networks is associated with increased knowledge and patient health activation. *Journal of medical Internet research 18*: pp. e212.

Gualtieri, L.N., 2009. The doctor as the second opinion and the internet as the first. In *CHI'09 Extended Abstracts on Human Factors in Computing Systems* (pp. 2489-2498).

Guidry, J.P., Jin, Y., Orr, C.A., Messner, M. and Meganck, S., 2017. Ebola on Instagram and Twitter: How health organizations address the health crisis in their social media engagement. *Public relations review, 43*(3), pp.477-486.

Gunn, J.M., Palmer, V.J., Dowrick, C.F., Herrman, H.E., Griffiths, F.E., Kokanovic, R., Blashki, G.A., Hegarty, K.L., Johnson, C.L., Potiriadis, M. and May, C.R., 2010. Embedding effective depression care: using theory for primary care organisational and systems change. *Implementation Science*, *5*(1), pp.1-15.

Gutierrez, N., Kindratt, T.B., Pagels, P., Foster, B. and Gimpel, N.E., 2014. Health literacy, health information seeking behaviours and internet use among patients attending a private and public clinic in the same geographic area. *Journal of community health, 39*(1), pp.83-89.

Haluza, D., Naszay, M., Stockinger, A. and Jungwirth, D., 2017. Digital natives versus digital immigrants: influence of online health information seeking on the doctor-patient relationship. *Health communication*, *32*(11), pp.1342-1349.

Harden, A., 2010. Mixed-methods systematic reviews: Integrating quantitative and qualitative findings. *Focus, 25*, pp.1-8.

Harris, M., Lawn, S.J., Morello, A., Battersby, M.W., Ratcliffe, J., McEvoy, R.D. and Tieman, J.J., 2017. Practice change in chronic conditions care: an appraisal of theories. *BMC health services research, 17*(1), pp. 1-10.

Hay, M.C., Strathmann, C., Lieber, E., Wick, K. and Giesser, B., 2008 Why patients go online: multiple sclerosis, the internet and physician-patient communication. *The Neurologist, 14*(6), pp.374-381

Health and Social Care Alliance Scotland, (2020). Home Page - Health and Social Care Alliance Scotland. [online] Available at: https://www.alliance-scotland.org.uk (accessed 26 October 26 2020).

Hernández-García, I. and Giménez-Júlvez, T., 2020. Assessment of health information about COVID-19 prevention on the internet: infodemiological study. *JMIR public health and surveillance, 6*(2), p.e18717.

Hoddy, E. T., 2019. Critical realism in empirical research: employing techniques from grounded theory methodology. *International Journal of Social Research Methodology*, *22*(1), 111-124.

Holloway, I. and Galvin, K., 2016. *Qualitative research in nursing and healthcare*. John Wiley & Sons.

Hong, Q.N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.P., Griffiths, F., Nicolau, B., O'Cathain, A. and Rousseau, M.C., 2018. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, *34*(4), pp.285-291.

Hou, J. and Shim, M., 2010. The role of provider-patient communication and trust in online sources in Internet use for health-related activities. *Journal of health communication*, *15*(sup3), pp.186-199.

Hu, Y. and Haake, J., 2010. Search your way to an accurate diagnosis: predictors of internet-based diagnosis accuracy. *Atlantic Journal of Communication, 18* (2), pp79-88.

Huisman, M., Joye, S. and Biltereyst, D., 2020. Searching for health: Doctor Google and the shifting dynamics of the middle-aged and older adult patient-physician relationship and interaction. *Journal of aging and health*, *32*(9), pp.998-1007.

Imes, R.S., Bylund, C.L., Sabee, C.M., Routsong, T.R. and Sanford, A.A., 2008. Patients' reasons for refraining from discussing internet health information with their healthcare providers. *Health communication*, *23*(6), pp.538-547.

Internet Live Stats (2018) 'Total number of Websites' [online] Available at: http://www.internetlivestats.com/total-number-of-websites/. (accessed August 21 2020).

Ip, E.J., Barnett, M.J., Tenerowicz, M.J. and Perry, P.J., 2010. The touro 12-step: a systematic guide to optimizing survey research with online discussion boards. Journal of medical Internet research, 12(2), p.e16.

Irani, E., 2019. The use of videoconferencing for qualitative interviewing: opportunities, challenges, and considerations. *Clinical Nursing Research 28*(1) pp. 3–8.

Ivankova, N.V., Creswell, J.W. and Stick, S.L., 2006. Using mixed-methods sequential explanatory design: From theory to practice. *Field methods*, *18*(1), pp.3-20.

Jacobson, M., 2015. *How Far Down the Search Engine Results Page Will Most People Go?* Available from: https://www.theleverageway.com/blog/how-far-down-the-search-engine-results-page-will-most-people-go/ (accessed September 21 2020).

James, N., & Busher, H., 2006. Credibility, authenticity and voice: Dilemmas in online interviewing. *Qualitative research*, *6*(3), pp. 403-420.

Jamshed, S., 2014. Qualitative research method-interviewing and observation. *Journal of basic and clinical pharmacy*, *5*(4), p.87.

Janghorban, R., Roudsari, R. L., & Taghipour, A., 2014. Skype interviewing: The new generation of online synchronous interview in qualitative research. *International journal of qualitative studies on health and well-being*, *9*(1), p. 24152.

Jayasinghe, R., Ranasinghe, S., Jayarajah, U. and Seneviratne, S., 2020. Quality of online information for the general public on covid-19'. *Patient education and counseling*, *103*(12), pp.2594-2597.

Jeong, J.S., Kim, Y. and Chon, M.G., 2018. Who is caring for the caregiver? The role of cybercoping for dementia caregivers. *Health communication*, *33*(1), pp.5-13.

Johnston, A. C., Worrell, J. L., di Gangi, P. M., & Wasko, M., 2013. Online health communities: An assessment of the influence of participation on patient empowerment outcomes. *Information Technology & People*, *26*(2), pp. 213–235

Johnston, B., McGill, M., Milligan, S., McElroy, D., Foster, C. and Kearney, N., 2009. Self care and end of life care in advanced cancer: literature review. *European Journal of Oncology Nursing*, *13*(5), pp.386-398.

Joseph-Williams, N., Lloyd, A., Edwards, A., Stobbart, L., Tomson, D., Macphail, S., Dodd, C., Brain, K., Elwyn, G. and Thomson, R., 2017. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *Bmj*, *357*.

Jowett, A., Peel, E., & Shaw, R. (2011). Online interviewing in psychology: Reflections on the process. *Qualitative Research in Psychology, 8*(4), pp. 354-369.

Jutel, A., Baker, M.G., Stanley, J., Huang, Q.S. and Bandaranayake, D., 2011. Self-diagnosis of influenza during a pandemic: a cross-sectional survey. *BMJ open, 1*(2), p.e000234.

Kahn, L.S., Vest, B.M., Madurai, N., Singh, R., York, T.R., Cipparone, C.W., Reilly, S., Malik, K.S. and Fox, C.H., 2015. Chronic kidney disease (CKD) treatment burden among low-income primary care patients. *Chronic illness, 11*(3), pp.171-183.

Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M., 2016. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of advanced nursing, 72*(12), pp. 2954-2965.

Kamel Boulos, M.N., Giustini, D.M. and Wheeler, S., 2016. Instagram and WhatsApp in health and healthcare: an overview. *Future Internet, 8*(3), p.37.

Kanagasundaram, N.S., Bevan, M.T., Sims, A.J., Heed, A., Price, D.A. and Sheerin, N.S., 2016. Computerized clinical decision support for the early recognition and management of acute kidney injury: a qualitative evaluation of end-user experience. *Clinical Kidney Journal, 9*(1), pp.57-62.

Kaufman S and Whitehead KA., 2018. Producing, ratifying, and resisting support in an online support forum. *Health 22* pp. 223-239.

Kaur, M., 2016. Application of mixed method approach in public health research. Indian journal of community medicine: official publication of Indian Association of Preventive & Social Medicine, 41(2), p.93.

Kelly, M., 2010. The role of theory in qualitative health research. Family practice, 27(3), pp.285-290.

Keselman, A., Browne, A.C. and Kaufman, D.R., 2008. Consumer health information seeking as hypothesis testing. *Journal of the American Medical Informatics Association, 15*(4), pp.484-495.

Kivunja, C. and Kuyini, A.B., 2017. Understanding and applying research paradigms in educational contexts. *International Journal of higher education, 6*(5), pp.26-41.

Klassen, K.M., Douglass, C.H., Brennan, L., Truby, H. and Lim, M.S., 2018. Social media use for nutrition outcomes in young adults: a mixed-methods systematic review. *International Journal of Behavioral Nutrition and Physical Activity,* 15(1), pp.1-18.

Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P. and Holecek, A., 2003. Online cancer support groups: a review of the research literature. *CIN: Computers, Informatics, Nursing, 21*(3), pp.136-142.

Koch-Weser, S., Bradshaw, Y.S., Gualtieri, L. and Gallagher, S.S., 2010. The Internet as a health information source: findings from the 2007 Health Information National Trends Survey and implications for health communication. *Journal of health communication, 15*(sup3), pp.279-293.

Krouwel, M., Jolly, K. and Greenfield, S., 2019. Comparing Skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome-an exploratory comparative analysis. BMC medical research methodology, 19(1), pp.1-9.

Kuehn, B., 2013. More than one-third of US individuals use the internet to self-diagnose. *The Journal of the American Medical Association, 209 (*8), pp.756-7.

Lambert, S.D. and Loiselle, C.G., 2007. Health information—seeking behavior. *Qualitative health research, 17(*8), pp.1006-1019.

Lanseng, E.J. and Andreassen, T.W., 2007. Electronic healthcare: a study of people's readiness and attitude toward performing self-diagnosis. *International Journal of Service Industry Management.*

Laugesen, J., Hassanein, K. and Yuan, Y., 2015. The impact of internet health information on patient compliance: a research model and an empirical study. *Journal of medical Internet research*, *17*(6), p.e143.

Lauri, M. A., 2019. WASP (Write a Scientific Paper): Collecting qualitative data using focus groups. *Early Human Development, 133*, pp. 65-68.

Lederman, R., Fan, H., Smith, S. and Chang, S., 2014. Who can you trust? Credibility assessment in online health forums. *Health Policy and Technology*, 3(1), pp.13-25.

Lee, K., Hoti, K., Hughes, J.D. and Emmerton, L., 2014. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of medical Internet research, 16*(12), p.e262.

Lee, K., Hoti, K., Hughes, J.D. and Emmerton, L.M., 2015. Consumer use of “Dr Google”: a survey on health information-seeking behaviors and navigational needs. *Journal of medical Internet research*, *17*(12), p.e288.

Leurer, M. D., & Misskey, E., 2015. “Be positive as well as realistic”: a qualitative description analysis of information gaps experienced by breastfeeding mothers. *International breastfeeding journal, 10*(1), p. 10.

Li, N., Orrange, S., Kravitz, R.L. and Bell, R.A., 2014. Reasons for and predictors of patients’ online health information seeking following a medical appointment. *Family practice, 31*(5), pp.550-556.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G., 2011. Paradigmatic controversies, contradictions, and emerging confluences, revisited. *The Sage handbook of qualitative research*, 4, pp. 97-128.

Lipscomb, M., 2010. Retroduction and retrodiction: Abductive inference in realist practice. Paper presented at ESRC funded seminar series: Critical Realism in Action Group Applied Methods for Social Mechanisms

Lipscomb, M., 2012. Abductive reasoning and qualitative research. *Nursing Philosophy, 13*(4), pp. 244-256.

Litzkendorf, S., Frank, M., Babac, A., Rosenfeldt, D., Schauer, F., Hartz, T. and Graf von der Schulenburg, J.M., 2020. Use and importance of different information sources among patients with rare diseases and their relatives over time: a qualitative study. *BMC Public Health, 20,* pp.1-14.

Lizarondo L, Stern C, Carrier J, Godfrey C, Rieger K, Salmond S, Apostolo J, Kirkpatrick P, Loveday H. Chapter 8: Mixed methods systematic reviews. In: Aromataris E, Munn Z

(Editors). JBI Manual for Evidence Synthesis. JBI, 2020. Available from https://synthesismanual.jbi.global. (accessed October 12 2020)

Lo, B. and Parham, L., 2010. The impact of web 2.0 on the doctor-patient relationship. Journal of Law, Medicine & Ethics, 38(1), pp.17-26.

Lobe, B., Morgan, D. and Hoffman, K.A., 2020. Qualitative data collection in an era of social distancing. *International Journal of Qualitative Methods, 19*, p.1609406920937875.

Lohse, B. and Wamboldt, P., 2013. Purposive Facebook recruitment endows cost-effective nutrition education program evaluation. *JMIR research protocols, 2*(2), p.e2713.

Longo, D.R., 2005. Understanding health information, communication, and information seeking of patients and consumers: a comprehensive and integrated model. *Health expectations: an international journal of public participation in health care and health policy*, *8*(3), p.189.

Longo, D.R., Schubert, S.L., Wright, B.A., LeMaster, J., Williams, C.D. and Clore, J.N., 2010. Health information seeking, receipt, and use in diabetes self-management. *The Annals of Family Medicine, 8*(4), pp.334-340.

Lu, X., Zhang, R., Wu, W., Shang, X. and Liu, M., 2018. Relationship between internet health information and patient compliance based on trust: empirical study. *Journal of medical Internet research*, *20*(8), p.e9364.

Lu, Y., Zhang, P., Liu, J., Li, J. and Deng, S., 2013. Health-related hot topic detection in online communities using text clustering. *Plos* one, 8(2), p.e56221.

Lustria, M.L.A., Smith, S.A. and Hinnant, C.C., 2011. Exploring digital divides: an examination of eHealth technology use in health information seeking, communication and personal health information management in the USA. *Health informatics journal, 17*(3), pp.224-243.

MacFarlane, A. and O'Reilly-de Brún, M., 2012. Using a theory-driven conceptual framework in qualitative health research. *Qualitative health research*, *22*(5), pp.607-618.

Macias, W. and McMillan, S., 2008. The return of the house call: The role of Internet-based interactivity in bringing health information home to older adults. *Health communication*, *23*(1), pp.34-44.

Madrigal, L. and Escoffery, C., 2019. Electronic health behaviors among US adults with chronic disease: cross-sectional survey. *Journal of medical Internet research*, 21(3), p.e11240.

Magilvy, J. K., & Thomas, E. (2009). A first qualitative project: Qualitative descriptive design for novice researchers. Journal for Specialists in Pediatric Nursing, 14(4), 298-300.

Mair, F.S., Browne, S., Morrison, D., Gallacher, K., Macleod, U. and May, C.R., 2011. Treatment Burden in end stage heart failure (ESHF): a qualitative study. *BMJ Supportive & Palliative Care, 1*(Suppl 1), pp. A8-A8.

Mamykina, L., Nakikj, D., & Elhadad, N. (2015). Collective sensemaking in online health forums. Paper presented at the Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems.

Marchal B., Dedzo M. & Kegels G., 2010. A realistic evaluation of the management of a well performing regional hospital in Ghana. *BMC Health Services Research, 10*(24), pp. 1-14

Marcu, A., Black, G. and Whitaker, K.L., 2018. Variations in trust in Dr Google when experiencing potential breast cancer symptoms: exploring motivations to seek health information online. *Health, Risk & Society, 20*(7-8), pp.325-341.

Marshall, C. and Rossman, G.B., 2014. *Designing qualitative research*. Sage publications.

May, C. and Finch, T. 2009. Implementing, embedding, and integrating practices: an outline of normalization process theory, *Sociology, 43*(3), pp.535-554.

May, C., Rapley, T., Mair, F., Treweek, S., Murray, E., Ballini, L., Finch, T.L., 2015. Normalization Process Theory on-line users' manual toolkit and NoMAD instrument. Retrieved from: http://www.normalizationprocess.org/.

May, C., Sibley, A. and Hunt, K., 2014. The nursing work of hospital-based clinical practice guideline implementation: an explanatory systematic review using Normalisation Process Theory. *International journal of nursing studies, 51*(2), pp.289-299.

May, C.R., Cummings, A., Girling, M., Bracher, M., Mair, F.S., May, C.M., Murray, E., Myall, M., Rapley, T. and Finch, T., 2018. Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implementation Science*, *13*(1), pp.1-27.

May, C.R., Mair, F., Finch, T., MacFarlane, A., Dowrick, C., Treweek, S., Rapley, T., Ballini, L., Ong, B.N., Rogers, A. and Murray, E., 2009. Development of a theory of implementation and integration: Normalization Process Theory. *Implementation Science*, *4*(1), pp.1-9.

McArdle H., 2015. 'Doctors "should not be intimidated" patients self-diagnosing online. Available at: https://www.heraldscotland.com/news/13207203.doctors-not-intimidated-patients-self-diagnosing-online/ (accessed March 16 2021).

McEvoy, R., Ballini, L., Maltoni, S., O'Donnell, C.A., Mair, F.S. and MacFarlane, A., 2014. A qualitative systematic review of studies using the normalization process theory to research implementation processes. *Implementation Science, 9*(1), pp.1-13.
McKenna, H.P., 1997. *Nursing models and theories*. London, UK: Routledge.

McLuhan, M. (1964) *Understanding Media*. Gingko Press, p 6

McPhail, G., and Lourie, M., 2017. Getting real: is realism a blind spot in research methodology?. *New Zealand Journal of Educational Studies, 52*(2), pp.285-299.

Mendes, Á., Abreu, L., Vilar-Correia, M.R. and Borlido-Santos, J., 2017. "That should be left to doctors, That's what they are there for!"—exploring the reflexivity and Trust of Young Adults When Seeking Health Information. Health communication, 32(9), pp.1076-1081.

Meyer, S.B., and Lunnay, B., 2013. The application of abductive and retroductive inference for the design and analysis of theory-driven sociological research. *Sociological research online, 18*(1), pp. 86-96.

Microsoft Corporation, 2018. Microsoft Excel, Available at: https://office.microsoft.com/excel. (accessed August 17 2020).

Milne, J., & Oberle, K., 2005. Enhancing rigor in qualitative description. *Journal of Wound Ostomy & Continence Nursing, 32*(6), pp. 413-420.

Minto, C., Bauce, B., Calore, C., Rigato, I., Folino, F., Soriani, N., Hochdorn, A., Iliceto, S. and Gregori, D., 2015. Is Internet use associated with anxiety in patients with and at risk for cardiomyopathy? American heart journal, 170(1), pp.87-95.

Modell, S., 2009. In defence of triangulation: a critical realist approach to mixed methods research in management accounting. *Manage Acc Res, 20*: pp.208-221.

Moore D and Ayers S., 2017. Virtual voices: social support and stigma in postnatal mental illness Internet forums. *Psychology, health & medicine 22* pp.546-551.

Morgan, A.J., Jorm, A.F. and Mackinnon, A.J., 2013. Internet-based recruitment to a depression prevention intervention: lessons from the Mood Memos study. *Journal of medical Internet research, 15*(2), p.e31.

Morgan, D.L., 1998. Practical strategies for combining qualitative and quantitative methods: Applications to health research. Qualitative health research, 8(3), pp.362-376.

Morrison, D. and Mair, F.S., 2011. Telehealth in practice: using Normalisation Process Theory to bridge the translational gap. *Primary care respiratory journal: journal of the General Practice Airways Group, 20*(4), p.351.

Muir Gray, J. A., 2002. *The Resourceful Patient*. Oxford, Rosetta Press

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J., 2009. Qualitative description–the poor cousin of health research? *BMC medical research methodology*, *9*(1), 52.

NHS Research Scotland, 2020. CSO Statement on Coronavirus (COVID-19) Impact on Research. Available from: https://www.nhsresearchscotland.org.uk/news/cso-statement-on-coronavirus-covid-19-impact-on-research. (accessed December 3 2020).

NHS, 2019. *Your Choices in the NHS*. Available from: https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs/. (accessed 14 November 2020).

NICE, 2018. Chronic heart failure in adults: diagnosis and management. Available at: https://www.nice.org.uk/guidance/ng106 (accessed 14 November 2020).

Nölke, L., Mensing, M., Krämer, A. and Hornberg, C., 2015. Sociodemographic and health-(care-) related characteristics of online health information seekers: a cross-sectional German study. *BMC public health*, *15*(1), pp.1-12.

North Central University Library (2021). *Research Process*. Available from: https://ncu.libguides.com/researchprocess/truncation. (accessed 3 March 2020).

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J., 2017. Thematic analysis: Striving to meet the trustworthiness criteria. International journal of qualitative methods, 16(1), 1609406917733847.

Nursing and Midwifery Council. 2015. The code, Professional standards of practice and behaviour for nurses, midwives and nursing associates. Available from: https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf (accessed 7 April 2020).

O'Connor, H. and Madge, C., (2017) Online Interviewing in Fielding, N.G., Lee, R.M., & Blank, G. (Eds.). (2017). *The SAGE handbook of online research methods*. Second Edition Sage.

O'Connor, H., Madge, C., Shaw, R., & Wellens, J., 2008. Internet-based interviewing. *The Sage handbook of online research methods*, pp. 271-289.

Ofcom (2015). *Scotland Becomes a 'Smartphone Society'*. Available from: https://www.ofcom.org.uk/about-ofcom/latest/media/media-releases/2015/cmr-scotland-2015#:~:text=Smartphones%20are%20now%20the%20most,into%20a%20'smartphone%20society'.&text=The%20proportion%20of%20premises%20in,at%2079.7%25%20in%20May%202015. (accessed September 4 2020).

Office for National Statistics, 2019 (ONS) Internet access – households and individuals, Great Britain: 2019 Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2019 (accessed 25th June 2020).

Oh, Y.S. and Cho, Y., 2015. Examining the relationships between resources and online health information seeking among patients with chronic diseases and healthy people. *Social work in health care, 54*(2), pp.83-100.

Ohana, S. and Barnoy, S., 2019. Israeli E-patients' Informational Needs. *Nursing outlook*, *67*(2), pp.190-198.

Pandey, A., Hasan, S., Dubey, D. and Sarangi, S., 2013. Smartphone apps as a source of cancer information: changing trends in health information-seeking behavior. *Journal of Cancer Education, 28*(1), pp.138-142.

Pappas, C. and Williams, I., 2011. Grey literature: its emerging importance. *Journal of Hospital Librarianship, 11*(3), pp.228-234.

Parahoo, K., 2014. *Nursing research: principles, process and issues*. Macmillan International Higher Education.

Park, B.K. and Calamaro, C., 2013. A systematic review of social networking sites: innovative platforms for health research targeting adolescents and young adults. *Journal of Nursing Scholarship, 45*(3), pp.256-264.

Parlour R. & McCormack B., 2012. Blending critical realist and emancipatory practice development methodologies: making critical realism work in nursing research. *Nursing Inquiry, 19,* pp. 308–321

Partners E., 2018. DistillerSR, Systematic Review and Literature Review Software by Evidence Partners Available from: https://www.evidencepartners.com/products/distillersr-systematic-review-software/ (accessed June 4 2020).

Perez, S.L., Kravitz, R.L., Bell, R.A., Chan, M.S. and Paterniti, D.A., 2016. Characterizing internet health information seeking strategies by socioeconomic status: a mixed methods approach. *BMC medical informatics and decision making, 16*(1), pp.1-9.

Perrin, A. and Duggan, M., 2015. Americans' internet access: 2000-2015. Pew Research Center, *26*(6), pp.1-12.

Pew Research Center. 2013. *Who's Not Online? 5 factors tied to the digital divide*. Available from: https://www.pewresearch.org/fact-tank/2013/11/08/whos-not-online-5-factors-tied-to-the-digital-divide/ (accessed January 4 2020)

Pew Research Center. 2016. *Social Media Update 2016*. Available from: https://www.pewresearch.org/internet/2016/11/11/social-media-update-2016/ (accessed January 4 2020).

Phillips D, 1987. *Philosophy, science, and social inquiry: contemporary methodological controversies in social science and related applied fields of research*. Pergamon Press, Oxford, England.

Pincock, S., 2003. Patients put their relationship with their doctors as second only to that with their families. *BMJ: British Medical Journal, 327*(7415), p.581.

Platt. J., 1981. On interviewing one's peers. *British Journal of Sociology 32*(1) pp. 75 - 91.

Plinsinga, M.L., Besomi, M., Maclachlan, L., Melo, L., Robbins, S., Lawford, B.J., Teo, P.L., Mills, K., Setchell, J., Egerton, T. and Eyles, J., 2019. Exploring the characteristics and preferences for online support groups: mixed method study. *Journal of medical Internet research, 21*(12), p.e15987.

Pluye P, Gagnon M-P, Griffiths F, Johnson-Lafleur J., 2009. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *J International journal of nursing studies. 46*(4):529-46.

Pluye, P., El Sherif, R., Granikov, V., Hong, Q.N., Vedel, I., Galvao, M.C.B., Frati, F.E., Desroches, S., Repchinsky, C., Rihoux, B. and Légaré, F., 2019. Health outcomes of online consumer health information: A systematic mixed studies review with framework synthesis. *Journal of the Association for Information Science and Technology, 70*(7), pp.643-659.

Polit, D. and Beck, C.T., 2014. Essentials of nursing research. *Appraising evidence for nursing practice, 8*.

Pourmand, G., Doshmangir, L., Ahmadi, A., Noori, M., Rezaeifar, A., Mashhadi, R., Aziminia, R., Pourmand, A. and Gordeev, V.S., 2020. An application of the theory of planned behavior to self-care in patients with hypertension. *BMC Public Health, 20*(1), pp.1-8.

Prensky, M., 2001. Digital natives, digital immigrants part 2: Do they really think differently?. On the horizon.

Procter, P.M., 2021. Patient Care, Information, Communication and Social Media Influencing Bias – A Discourse. In *Informatics* (Vol. 8, No. 2, p. 28). Multidisciplinary Digital Publishing Institute.

PROSPERO. International prospective register of systematic reviews 2018. Available from: https://www.crd.york.ac.uk/prospero/. (accessed April 3 2019).

QSR International Pty Ltd. (2020) NVivo (released in March 2020), Available at: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home (accessed October 5 2020)

Qudah, B. and Luetsch, K., 2019. The influence of mobile health applications on patient-healthcare provider relationships: a systematic, narrative review. *Patient education and counseling, 102*(6), pp.1080-1089.

Rahmqvist, M. and Bara, A.C., 2007. Patients retrieving additional information via the Internet: A trend analysis in a Swedish population, 2000—05. *Scandinavian Journal of Public Health*, *35*(5), pp.533-539.

Ramo, D.E., Hall, S.M. and Prochaska, J.J., 2010. Reaching young adult smokers through the internet: comparison of three recruitment mechanisms. *Nicotine & Tobacco Research, 12*(7), pp.768-775.

Ritchie, J. and Lewis, J., 2003. *Qualitative Research Practice*. Sage Publications, London.

Rockliffe, L., Chorley, A. J., Marlow, L. A., & Forster, A. S., 2018. It’s hard to reach the “hard-to-reach”: the challenges of recruiting people who do not access preventative healthcare services into interview studies. *International journal of qualitative studies on health and well-being, 13(*1), 1479582.

Roper, J. M., & Shapira, J. (2000). Ethnography in nursing research (Vol. 1). Sage.

Rupert DJ, Moultrie RR, Read JG, Amoozegar JB, Bornkessel AS, O’Donoghue AC, et al., 2014. Perceived healthcare provider reactions to patient and caregiver use of online health communities. *J Patient education counseling. 96*(3):320-6.

Russ, H., Giveon, S.M., Granek Catarivas, M. and Yaphe, J., 2011. The effect of the Internet on the patient-doctor relationship from the patient's perspective: a survey from primary care. *IMAJ-Israel Medical Association Journal*, *13*(4), p.220.

Sabater-Galindo, M., Fernandez-Llimos, F., Sabater-Hernández, D., Martínez-Martínez, F. and Benrimoj, S.I., 2016. Healthcare professional-patient relationships: Systematic review of theoretical models from a community pharmacy perspective. *Patient education and counseling*, *99*(3), pp.339-347.

Sadasivam, R.S., Kinney, R.L., Lemon, S.C., Shimada, S.L., Allison, J.J. and Houston, T.K., 2013. Internet health information seeking is a team sport: analysis of the Pew Internet Survey. *International journal of medical informatics*, *82*(3), pp.193-200.

Salmons, J., 2012. Designing and conducting research with online interviews. *Cases in online interview research*, pp.1-30.

Samkange-Zeeb, F., Borisova, L., Padilla, B., Bradby, H., Phillimore, J., Zeeb, H. and Brand, T., 2020. Superdiversity, migration and use of internet-based health information-results of a cross-sectional survey conducted in 4 European countries. *BMC public health*, *20*(1), pp.1-12.

Sandelowski, M., 2000. Whatever happened to qualitative description?. *Research in nursing & health*, *23*(4), pp.334-340.

Sarantakos, S., 2012. *Social research*. Macmillan International Higher Education.

Sarkar, U., Karter, A.J., Liu, J.Y., Adler, N.E., Nguyen, R., Lopez, A. and Schillinger, D., 2010. The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system—results from the Diabetes Study of Northern California (DISTANCE). *Journal of health communication, 15*(S2), pp.183-196.

Sarrazin, M. S. V., Cram, P., Mazur, A., Ward, M., & Reisinger, H. S. (2014). Patient perspectives of dabigatran: analysis of online discussion forums. The Patient-Patient-Centered Outcomes Research, 7(1), pp. 47-54.

Schiller, C.J., 2016. Critical realism in nursing: an emerging approach. *Nursing Philosophy, 17*(2), pp.88-102.

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of qualitative research*, 1, pp. 118-137.

Scottish Household Survey 2014 (2015) 'Scotland's People Annual Report: Internet' [Online] Available at: http://www.gov.scot/Publications/2015/08/3720/8. (accessed August 13 2020).

Shabahang, R., Aruguete, M.S. and McCutcheon, L.E., 2020. Online health information utilization and online news exposure as predictor of COVID-19 anxiety. *N. Am. J. Psychol*, *22*(3), pp.469-482.

Sharma, G., 2017. Pros and cons of different sampling techniques. *International journal of applied research*, *3*(7), pp.749-752.

Shaw, RL, 2010. Embedded reflexivity within experiential qualitative psychology, *Qualitative Research in Psychology, 7*(3), pp. 233–243

Shmueli, G. and Koppius, O.R., 2011. Predictive analytics in information systems research. *MIS quarterly*, pp.553-572.

SIGN. (2016). Management of chronic heart failure. Available at: https://www.sign.ac.uk/assets/sign147.pdf (accessed September 23 2020).

Silver M.P., 2015. Patient perspectives on online health information and communication with doctors: a qualitative study of patients 50 years old and over. *Journal of medical Internet research*. *17*(1).

Silverman, D., 1985. *Qualitative methodology and sociology: Describing the social world*. Gower publishing company.

Simblett, S., Greer, B., Matcham, F., Curtis, H., Polhemus, A., Ferrão, J., Gamble, P. and Wykes, T., 2018. Barriers to and facilitators of engagement with remote measurement technology for managing health: systematic review and content analysis of findings. *Journal of medical Internet research*, 20(7), p.e10480.

Singh, S. and Banerjee, A., 2019. Internet and doctor-patient relationship: Cross-sectional study of patients' perceptions and practices. *Indian journal of public health*, *63*(3), p.215.

Sinnenberg, L., Buttenheim, A.M., Padrez, K., Mancheno, C., Ungar, L. and Merchant, R.M., 2017. Twitter as a tool for health research: a systematic review. American journal of public health, 107(1), pp.e1-e8.

Smith, J. A., Flowers, P. & Larkin, M. 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*, London, Sage.

Smith, J., & Firth, J. 2011. Qualitative data analysis: the framework approach. *Nurse researcher*, *18*(2), pp.52-62.

Smith, S.G., Pandit, A., Rush, S.R., Wolf, M.S. and Simon, C., 2015. The association between patient activation and accessing online health information: results from a national survey of US adults. *Health Expectations*, 18(6), pp.3262-3273.

Snyder, C.F., Wu, A.W., Miller, R.S., Jensen, R.E., Bantug, E.T. and Wolff, A.C., 2011. The role of informatics in promoting patient-centered care. *Cancer Journal 17*(4), p.211.

Social Science Research Council (SSRC) (2020) Resuming Field Research in Pandemic Times. Available at: https://items.ssrc.org/covid-19-and-the-social-sciences/social-research-and-insecurity/resuming-field-research-in-pandemic-times/ (accessed 20th July 2020)

Sommerhalder K, Abraham A, Zufferey MC, Barth J, Abel T., 2009. Internet information and medical consultations: Experiences from patients' and physicians' perspectives. *Patient Education and Counseling*. *77*(2):266-71.

Statista (2021) UK: smartphone ownership by age from 2012-2017 [online] Available at: https://www.statista.com/statistics/271851/smartphone-owners-in-the-united-kingdom-uk-by-age/. (accessed January 4 2021).

Statista, (2019). Number of monthly active Twitter users worldwide from 1st quarter 2010 to 1st quarter 2019. Available from: https://www.statista.com/statistics/282087/number-of-monthly-active-twitter-users/ (accessed January 4 2021).

Statista, (2021). Number of Monthly Active Facebook Users Worldwide as of 4th Quarter 2020. Available from: https://www.statista.com/statistics/264810/number-of-monthly-active-facebook-users worldwide/#:~:text=With%20roughly%202.8%20billion%20monthly,the%20biggest%20social%20network%20worldwide. (accessed January 4 2021).

Stevenson F.A., Kerr C., Murray E., Nazareth I., 2007. Information from the Internet and the doctor-patient relationship: the patient perspective – a qualitative study. *J BMC Family Practice*. *8*(1) p.47.

Strauss, A. and Corbin, J.M., 1997. *Grounded theory in practice*. Sage.

Stuckey, H.L., 2013. Three types of interviews: Qualitative research methods in social health. *Journal of Social Health and Diabetes, 1*(02), pp.056-059.

Sudau, F., Friede, T., Grabowski, J., Koschack, J., Makedonski, P. and Himmel, W., 2014. Correction: Sources of Information and Behavioral Patterns in Online Health Forums: Observational Study. Journal of medical Internet research, 16(1), p.e39.

Sullivan, C.F., 2003. Gendered cybersupport: A thematic analysis of two online cancer support groups. *Journal of health psychology, 8*(1), pp.83-104.

Sweet, P.L., 2020. Who Knows? Reflexivity in Feminist Standpoint Theory and Bourdieu. *Gender & Society*, *34*(6), pp.922-950.

Tan, S. S.-L., & Goonawardene, N., 2017. Internet health information seeking and the patient-physician relationship: a systematic review. *Journal of medical Internet research, 19*(1), p. e9.

Tang, L. and Zou, W., 2021. Health information consumption under COVID-19 lockdown: An interview study of residents of Hubei Province, China. *Health Communication, 36*(1), pp.74-80.

Tardy, R. W., & Hale, C. L. (1998). Getting ―plugged in: A network analysis of health-information seeking among "stay-at-home moms". *Communication Monographs, 65*(4) pp. 336-357.

Tariq, S. and Woodman, J., 2013. Using mixed methods in health research. *JRSM short reports, 4*(6), p.2042533313479197.

The Medical and Dental Defence Union of Scotland, 2015. 'Data explosion leading to more "worried well"' Available at: http://www.mddus.com/news/news-digest/2015/january/data-explosion-leading-to-more-worried-well/. (accessed March 4 2020).

The Pharmaceutical Journal, 2017. Online:DOI:10.1211/PJ.2017.20203923

Thomas, V.L., Chavez, M., Browne, E.N. and Minnis, A.M., 2020. Instagram as a tool for study engagement and community building among adolescents: A social media pilot study. *Digital health, 6*, p.2055207620904548.

Thorne, S., Con, A., McGuinness, L., McPherson, G. and Harris, S.R., 2004. Health care communication issues in multiple sclerosis: an interpretive description. *Qualitative health research, 14*(1), pp.5-22.

Tolson D., McIntosh J., Loftus L. et al. (2007) Developing a managed clinical network in palliative care: a realistic evaluation. *International Journal of Nursing Studies, 44* (2), 183–195.

Tong, A., Sainsbury, P. & Craig, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*, pp. 349-357.

Townsend, A., Leese, J., Adam, P., McDonald, M., Li, L.C., Kerr, S. and Backman, C.L., 2015. eHealth, participatory medicine, and ethical care: a focus group study of patients' and health care providers' use of health-related internet information. *Journal of medical Internet research, 17*(6), p.e155.

Tran, B.X., Dang, A.K., Thai, P.K., Le, H.T., Le, X.T.T., Do, T.T.T., Nguyen, T.H., Pham, H.Q., Phan, H.T., Vu, G.T. and Phung, D.T., 2020. Coverage of health information by different sources in communities: implication for COVID-19 epidemic response. *International journal of environmental research and public health, 17*(10), p.3577.

Tumasjan, A., Sprenger, T., Sandner, P. and Welpe, I., 2010, May. Predicting elections with twitter: What 140 characters reveal about political sentiment. In Proceedings of the International AAAI Conference on Web and Social Media 4(1).

Tustin, N., 2010. The role of patient satisfaction in online health information seeking. *Journal of health communication, 15*(1), pp.3-17.

University of Glasgow., 2020. Coronavirus: Information for students and staff. Available from: https://www.gla.ac.uk/myglasgow/coronavirus/faqs/ [access 20 March 2020].

Van Uden-Kraan, C.F., Drossaert, C.H., Taal, E., Smit, W.M., Moens, H.J.B., Siesling, S., Seydel, E.R. and Van de Laar, M.A., 2009. Health-related internet use by patients with somatic diseases: frequency of use and characteristic of users. *Informatics for Health and Social Care, 34*(1), pp.18-29.

Varaki, B. S., & Earl, L., 2005. Epistemic fallacy in educational research. *Masalah Pendidikan*, *28*, pp. 279-288.

Wand T., White K. & Patching J., 2010. Applying a realist(ic) framework to the evaluation of a new model of emergency department based mental health nursing practice. *Nursing Inquiry, 17*(3), pp. 231–239.

Wang, J., Ashvetiya, T., Quaye, E., Parakh, K. and Martin, S.S., 2018. Online health searches and their perceived effects on patients and patient-clinician relationships: a Systematic review. *The American journal of medicine, 131*(10), pp.1250-e1.

Waring, M.E., McManus, D.D., Amante, D.J., Darling, C.E. and Kiefe, C.I., 2018. Online health information seeking by adults hospitalized for acute coronary syndromes: Who looks for information, and who discusses it with healthcare providers? *Patient education and counseling, 101*(11), pp.1973-1981.

Warner, J. (2011). Too much information can be dangerous, not empowering. *Nursing Times, 107*, 13.

White, R. W., & Horvitz, E., 2009. Experiences with web search on medical concerns and self diagnosis. In AMIA annual symposium proceedings (Vol. 2009, p. 696). American Medical Informatics Association.

Whitehead, D. Dilworth, S. and Higgins, I., 2016. Common qualitative methods In Schneider, Z., Whitehead, D., LoBiondo-Wood, G., Faan, P. R., Haber, J., & Faan, P. R. *Nursing and midwifery research: Methods and appraisal for evidence-based practice*. Elsevier.

Wilkinson, S., Joffe, H., & Yardley, L., 2004. Qualitative data collection: interviews and focus groups. *Research methods for clinical and health psychology*, 39-55.

Williams, L., Rycroft-Malone, J., & Burton, C. R., 2017. Bringing critical realism to nursing practice: Roy Bhaskar's contribution. *Nursing Philosophy, 18*(2), e12130.

Willis, E., 2014. The making of expert patients: the role of online health communities in arthritis self-management. *Journal of health psychology, 19*(12), pp.1613-1625.

Wilson V. & McCormack B., 2006. Critical realism as emancipatory action: the case for realistic evaluation in practice development. *Nursing Philosophy, 7*(1), 45– 57.

Wilson, R. L., Carryer, J., Dewing, J., Rosado, S., Gildberg, F., Hutton, A., and Sheridan, N., 2020. The state of the nursing profession in the International Year of the Nurse and Midwife 2020 during COVID-19: A Nursing Standpoint. *Nursing Philosophy, 21*(3).

Wong, D.K.K. and Cheung, M.K., 2019. Online health information seeking and ehealth literacy among patients attending a primary care clinic in Hong Kong: A cross-sectional survey. *Journal of medical Internet research, 21*(3), p.e10831.

World Health Organization. Regional Office for Europe, Health Evidence Network, European Observatory on Health Systems and Policies, Sorenson, Corinna, Drummond, Michael. et al., 2008. How can the impact of health technology assessments be enhanced? World Health Organization. Regional Office for Europe. Available at: https://apps.who.int/iris/handle/10665/107981 (accessed November 4 2020).

Xiao, N., Sharman, R., Rao, H.R. and Upadhyaya, S., 2014. Factors influencing online health information search: An empirical analysis of a national cancer-related survey. *Decision Support Systems, 57*, pp.417-427.

Yavan, T., 2015. Online access to health information: How is it safe?. *Balkan Military Medical Review, 18*(1).

Zhang, Z., Yang, H., He, J., Lu, X. and Zhang, R., 2021. The Impact of Treatment-Related Internet Health Information Seeking on Patient Compliance. *Telemedicine and e-Health*, *27*(5), pp.513-524.

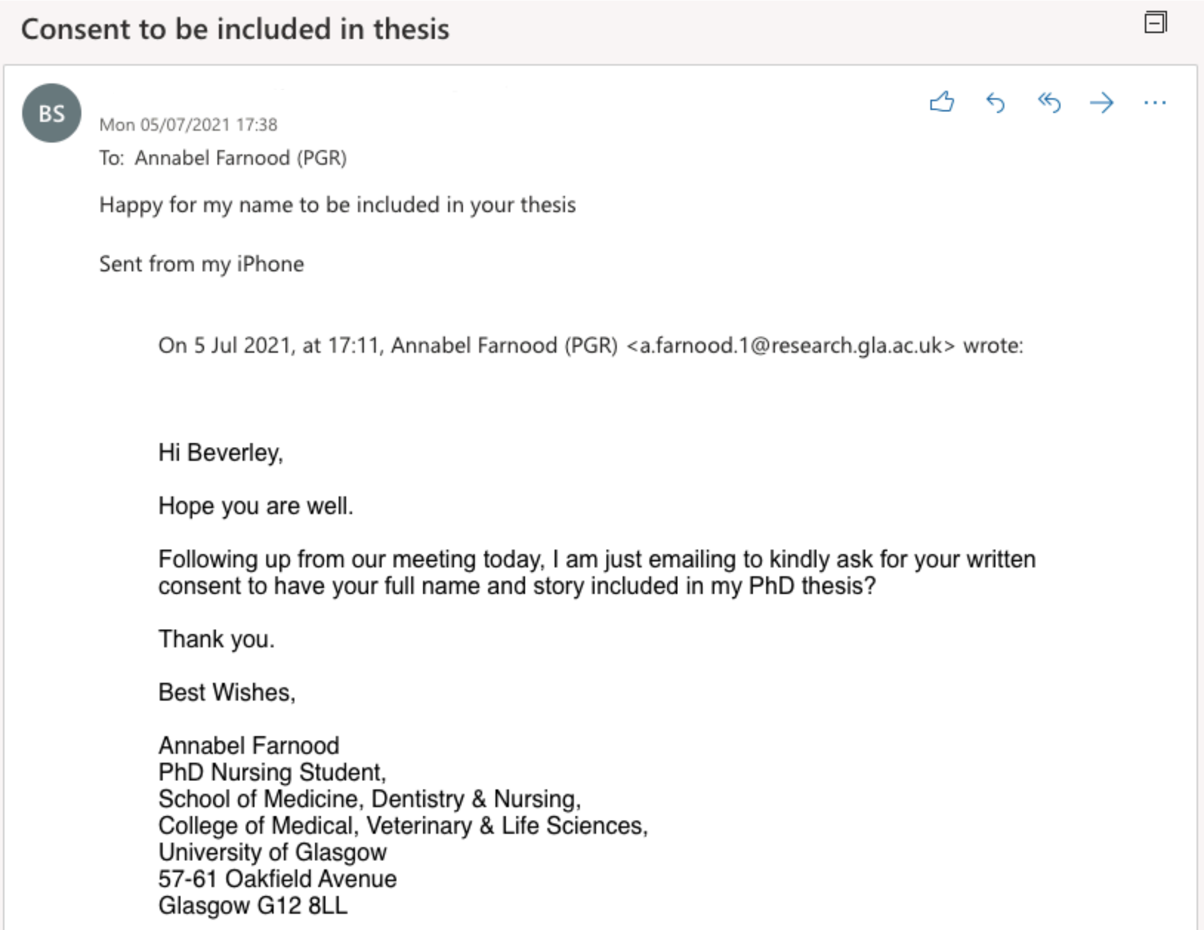
Zhao, Y. and Zhang, J., 2017. Consumer health information seeking in social media: a literature review. *Health Information & Libraries Journal, 34*(4), pp.268-283.

Ziebland S and Wyke S., 2012. Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *The Milbank Quarterly 90* pp. 219-249.

Zoom Video Communications Inc. (2016). Security Guide. Zoom Video Communications Inc. Available at: https://d24cgw3uvb9a9h.cloudfront.net/static/81625/doc/Zoom-Security-White-Paper.pdf (accessed September 21 2020).

Appendices

Appendix 1: PPI consent to be included in this PhD thesis (verbal consent also gained)



Consent to be included in thesis

Mon 05/07/2021 17:38

To: Annabel Farnood (PGR)

Happy for my name to be included in your thesis

Sent from my iPhone

On 5 Jul 2021, at 17:11, Annabel Farnood (PGR) <a.farnood.1@research.gla.ac.uk> wrote:

Hi Beverley,

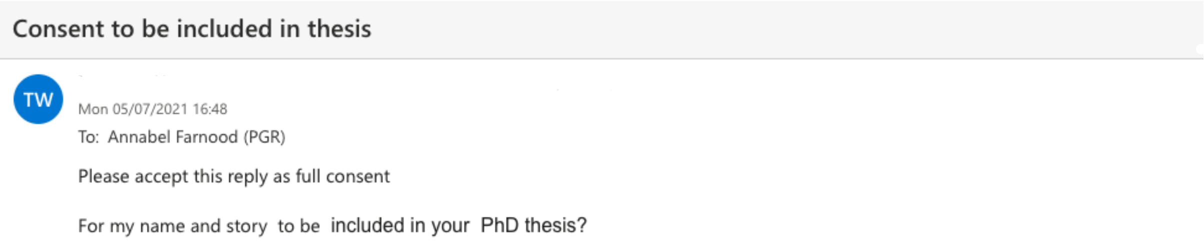
Hope you are well.

Following up from our meeting today, I am just emailing to kindly ask for your written consent to have your full name and story included in my PhD thesis?

Thank you.

Best Wishes,

Annabel Farnood
PhD Nursing Student,
School of Medicine, Dentistry & Nursing,
College of Medical, Veterinary & Life Sciences,
University of Glasgow
57-61 Oakfield Avenue
Glasgow G12 8LL



Consent to be included in thesis

Mon 05/07/2021 16:48

To: Annabel Farnood (PGR)

Please accept this reply as full consent

For my name and story to be included in your PhD thesis?

Appendix 2: PPI recruitment flyer

University of Glasgow

Patient and Public Involvement

CAN YOU HELP WITH A PHD PROJECT?
DO YOU ONLINE SELF-DIAGNOSE?

Have you ever used the internet to self-diagnose? Have you ever used the internet to self-diagnose heart failure/heart disease OR any long term condition for yourself or someone else?

Would you like to have you say on a research project investigating the effect of online self-diagnosis?

Annabel Farnood
Email : a.farnood.1@research.gla.ac.uk Twitter: @AnnabelFarnood
PhD Nursing Student,
School of Medicine, Dentistry & Nursing,
College of Medical, Veterinary & Life Sciences,
University of Glasgow

University of Glasgow

My name is Annabel Farnood and I am a PhD nursing student at the University of Glasgow. My PhD research project is about understanding the effect of online self-diagnosis and how this impacts the public/patient-healthcare professional relationship.

What is patient and public involvement and why is it important in research?

- Allows service user to make an impact in their own care and treatment
- Provide their input for the way services are operated
- Help to improve the healthcare system
- PPI members will gain increased knowledge, skills, confidence, personal support and emotional and practical demands of members.

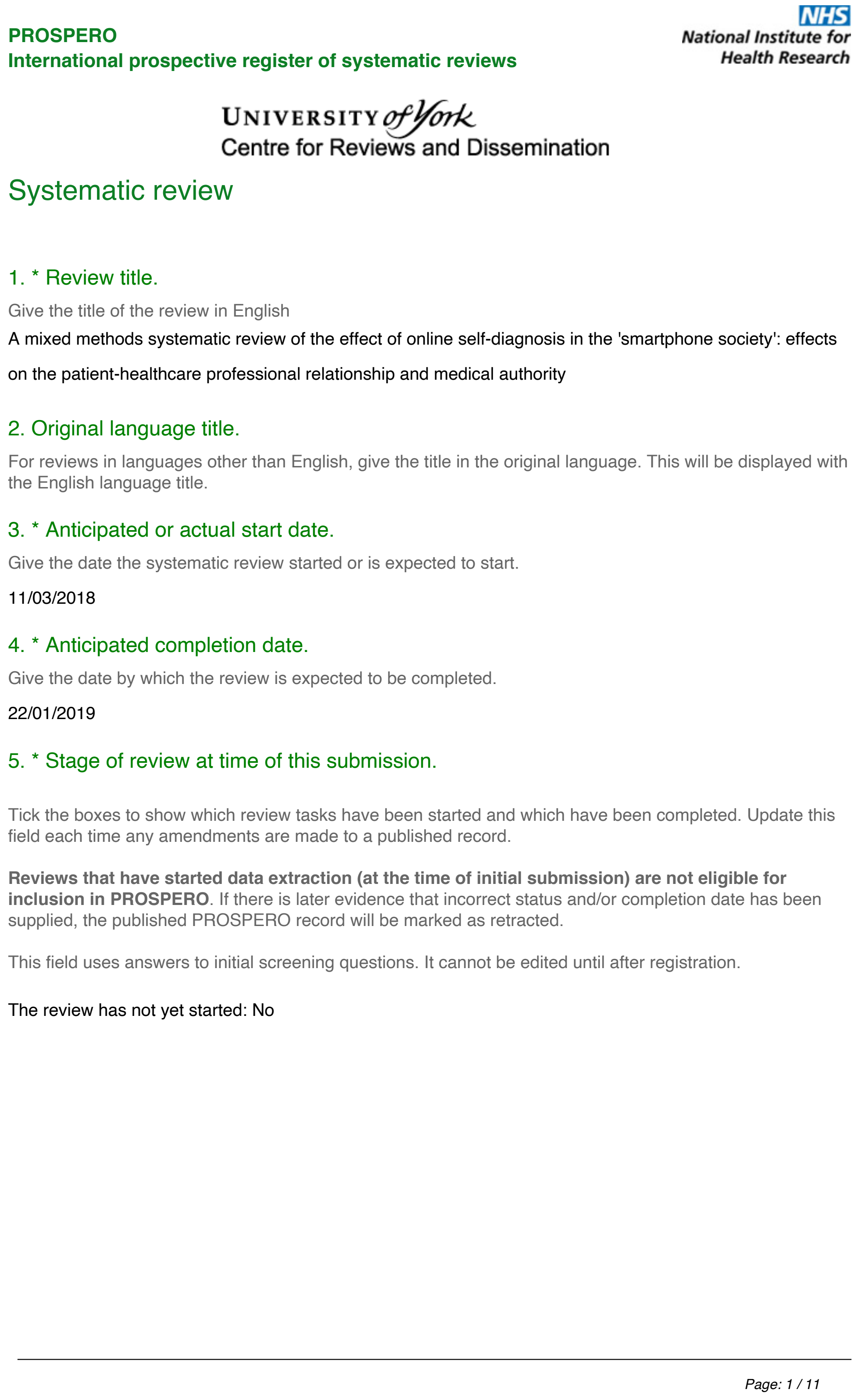
What you may be involved in?

- Creating recruitment strategies
- Help conduct interviews
- Review writing styles
- Attend conferences
- Deliver your opinion and ideas to help with the research project
- Join in with other research public involvement advisors

What do you have to do?

The researcher will make this process simple for you. The researcher will work around your schedule and meet at a time an place that is convenient for you. Our research group (led by Professor Johnston) will reimburse advisors at NIHR(National Institute of Health Research) Involve rates.

Appendix 3: PROSPERO International Prospective Register of Systematic Reviews (CRD42018084230)



PROSPERO
International prospective register of systematic reviews

National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the title of the review in English

A mixed methods systematic review of the effect of online self-diagnosis in the 'smartphone society': effects on the patient-healthcare professional relationship and medical authority

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

11/03/2018

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

22/01/2019

5. * Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

This field uses answers to initial screening questions. It cannot be edited until after registration.

The review has not yet started: No

Review stage	**Started**	**Completed**
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Annabel Farnood

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Miss Farnood

7. * Named contact email.

Give the electronic email address of the named contact.

a.farnood.1@research.gla.ac.uk

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+44 (0)141 330 4621

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Glasgow

Organisation web address:

https://www.gla.ac.uk/

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Professor Bridget Johnston. The University of Glasgow
Professor Frances Mair. The University of Glasgow

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

The University of Glasgow

Grant number(s)

State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

1. What are the effects of patients seeking online health information on the healthcare professional-patient relationship and medical consultation?

2. How do healthcare professionals perceive patients use of online health information?

3. How do public/patients perceive the use of online health information?

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

Five databases were used to perform the literature search: MEDLINE, EMBASE, Scopus, ACM Digital Library and CINAHL. Searches were focused on three main concepts being digital health, online health information and patient-professional relationship.

Backward and forward citation chaining will be conducted and additional studies will be identified from references lists of included studies.

Restrictions:

- English language only;

- Publication date from 2007 and onwards;

- Participants under the age of 18;

- Study types that are secondary analysis or grey literature, dissertation/thesis, reviews, published abstracts or conference proceedings, commentary articles written to propose opinions and letters or editorials will be excluded;

- Studies focused on mental health conditions, cancer, complementary alternative medicines, pregnancy related, parents seeking information about children's healthcare, plastic surgery/cosmetic surgery, surgical procedures and before and after management of procedures will be excluded;
- Hospital and any unordinary settings;
- Studies that will be excluded will be those that include technology interventions (e.g. Heart monitors) and clinical decision support systems for health care professionals.

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Health information seeking and self-diagnosis is a growing phenomenon alongside technology advancement. It is important to understand whether patient empowerment and engagement through access to effectively the same knowledge bank as healthcare professionals, brings positive benefits or undermines the relationship between healthcare professionals and the patient. The primary reason for a patient attending a GP appointment is to seek a diagnosis and for the GP to offer a diagnosis and then recommend treatment. However, with the large volumes of information currently available on the World Wide Web, it makes it convenient for non-experts to manage their own health assessment and self-diagnosis, which can have a relative impact in consultations and on the physician/healthcare relationship. There is a similar potential for an impact on the nurse-patient relationship. This mixed methods systematic review will comprehensively cover the literature that explores the effects of online health information and self-diagnosis on the patient-healthcare professional relationship.

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Any individual (adult) over the age of 18. This includes patients, the public and health care professionals.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

To understand the usage of the internet for self-diagnosis and information seeking for any physical health condition with the exclusion of cancer, and how this may impact the healthcare professional-patient relationship.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable.

22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Study types to be included will be those that are published from 2007 - present; English language only; studies that report primary data (qualitative and quantitative studies); studies can use any form of qualitative or quantitative methods.

Participants: Any individual (adult) over the age of 18. This includes patients, the public and health care professionals.

Topic: Any physical health condition excluding cancer (as this will not be a condition observed throughout this research). Must be in relation to online self-diagnosing and information seeking on the internet. Can include any level of the diagnostic process. Can include the perceptions of the public and healthcare professionals of patients' use of online forums to communicate health information and use of the internet for self-diagnosing.

Setting: Any primary care or community/home setting.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Primary and community care settings and any countries will be included.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Effects on healthcare professional-patient relationship and medical authority.

Patients and health care professionals' perceptions of patients seeking health information online.

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None.

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

One researcher independently screened title and abstracts to identify relevant and exclude irrelevant articles. Full-text versions of journal articles that are not excluded at this point will be gathered and assessed for eligibility and will be double reviewed using Distiller software. Discrepancies will be subject to discussion, with a record made of how the decisions were reached. Articles will be coded to indicate which review question they address.

Data extraction will be accomplished by using a standardised data extraction template which will be created using the main characteristics of the review, including the author, year and country, methodological approaches taken, aims of the study, sample size, settings and key findings. A separate table will be formulated for the population characteristics of the studies included. Any discrepancies will be reviewed by the third researcher.

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

A quality assessment will be used applying the mixed methods appraisal tool (Hong et al, 2018) to assess the quality of studies. The second researcher will undertake random 'spot' checks for reliability purposes. Discussion will be engaged on any discrepancies with a record of how the decisions were reached. Studies will not be excluded from the review based on the quality scores, however, will be reported in the findings.

Hong, Q.N., Pluye, P., Fabregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.P., Griffiths, F., Nicolau, B. and O'Cathain, A., Mixed Methods Appraisal Tool (MMAT) Version 2018.

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

The findings of qualitative and quantitative studies will be separately tabulated, and these tables will form the basis of a discussion of the findings. Subsequently, a critical analysis of both qualitative and quantitative findings will be conducted and used to develop an initial hypothesis for the effect of online self-diagnosis and health information seeking on the healthcare professional-patient relationship.

The included studies will be read and a thematic analysis will be undertaken using 'NVivo', to establish a list of themes and sub-themes. The appropriateness of the themes identified will be verified by the second researcher.

29. * Analysis of subgroups or subsets.

State any planned investigation of ‘subgroups’. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

None planned.

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Living systematic review
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

COVID-19
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
Yes

Rehabilitation
No

Respiratory disorders
No

Service delivery
Yes

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is an English language summary.

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

Scotland

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

Following this report for review, it will be made accessible online. If my findings influence a change in practice this will be sent to the leads of the National Health Service.

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Online health information; medical information; internet; information seeking; self-diagnosis; digital health; professional-patient relationship.

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published.New registrations must be ongoing so this field is not editable for initial submission.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.

Appendix 4: MEDLINE search strategy

1. exp Health Knowledge, Attitudes, Practice/
2. exp Internet/
3. exp Telemedicine
4. exp Medical Informatics
5. exp Information Systems/
6. exp Cell Phone/
7. (Tele?Health or digital health or eHealth).tw.
8. (computer assisted or cyber* or “e-health” or technolog* or (electronic adj health)).tw.
9. (mobilephone) or (mobile adj phone*) or cellphone or (cell adj phone*) or smartphone or (smart adj phone*)).tw.
10. (Mobile app* or twitter or facebook or social media or search engine* or online forum).tw.
11. (iPhone or i-phone or iphone or android).tw.
12. or/1-11
13. exp Information Seeking Behavior/
14. (Diagnos* or self?diagnos*).tw.
15. ((online or web* or internet) and diagnos* or self?diagnos*)).tw.
16. (Medical seeking or medical information or medical search or medical information website or symptom check*).tw.

17. (Health literacy or health information or health search or information seeking or health information website.tw.

18. or/13-17

19. exp Professional-Patient Relations/

20. (((Doctor* or nurs* or GP* or general practitioner* or physician* or healthcare professional* or health professional* or health-care professional* or healthcare provider*) and patient*) adj5 relation*).tw.

21. (physician* perception* or physician* opinion* or doctor* perception* or doctor* opinion* or nurs* perception* or nurs* opinion* or healthcare professional* perception* or healthcare professional* opinion* or health professional perception* or health professional opinion* or patient* perception* or patient* opinion*).tw.

22. or/19-21

23. 12 and 18 and 22

24. limit 23 to (english language and yr="2007-Current")

Appendix 5: Qualitative data extraction table

Author/Year/Country	Aims of study	Methods & Quality	Participants	Settings	Key findings
Ahluwalia et al. (2010), UK	Examine the responses of GPs to internet prepared patients in consultations and what strategies GPs use for dealing with internet information being brought to the consultation.	Ethical consideration not reported. **Methodology:** Phenomenological. **Data collection method:** Semi-structured interviews. Framework approach to analysis used. MMAT = 3 (moderate).	Purposive sampling. 11 GPs. Five partners, three locum and three salaried doctors. Seven were white, three Asian and one Chinese.	Primary care GP practices.	GPs had a tendency to experience anxiety when patients brought health information from the internet to appointments, but they were able to resolve the anxiety with several techniques. They learned to distance themselves from their emotional response and used cognitive and behavioural techniques to respond effectively to patients. Doctors perceived it as important to still feel of value

					to their patients as this was an effect on the doctor-patient relationship.
Benetoli et al. (2018), Australia	Explores the use of social media and its potential impact on patient’s interactions with healthcare professionals.	Ethical consideration not reported. **Methodology:** Phenomenology. **Data collection method:** 5 focus groups conducted. Thematic analytic approach used. MMAT = 4 (moderate-high).	36 participants with a range of chronic conditions from hypertension, depression, arthritis and Crohn’s disease), on medications and use social media for health seeking purposes.	Setting not explicitly stated.	Participants did not tend to interact with healthcare professionals on social media and only used this to talk to peers. They reported they felt that the patient-HCP relationship had improved as they felt a sense of empowerment and increased knowledge from internet information. They mainly used it to prepare for consultations.
Bowes et al. (2012), UK	Explores patient’s reasons	**Qualitative**	26 participants.	Primary care – GP surgery.	Participants reported their use of the internet was to stay well

	for presenting information at medical consultations and their perceptions of the GPs responses and what they wanted from their doctor.	Ethical consideration not reported. **Methodology:** Phenomenology. **Data collection method:** Semi-structured interviews. Inductive analytic approach. MMAT = 3 (moderate)			informed about their health and make use of the time spent with the GP. Patients expected GPs to acknowledge their found information and discuss it. However, if the GP did not seem interested in their found information, patients reported damage to the doctor-patient relationship. Although, patients tended to value the opinion of the GP more than the internet.
Caiata-Zufferey and Schulz. (2012), Switzerland	Explores the strategies performed by physicians when interacting with	Ethical approval obtained. **Methodology:** Phenomenology. **Data collection method:**	17 physicians. 5 general practitioners, 3 gynaecologists, 2 orthopaedic	Primary care and medical specialist practices.	Results argue that physician's communicative strategies are partly 'personality dependent' or 'context-dependent'. Most physicians in this study found

	internet informed patients and defines the motives behind their strategies.	Semi-structured interviews. Inductive analytic approach. MMAT = 5 (high).	surgeons, 2 urologists, 2 oncologists, 1 allergist and 1 rheumatologist.		their consultations to be disrupted by patients who introduce online health information. It is reported that the internet can impact the patient-doctor relationship depending on the physician's responses and the patient's expectation.
Caiata-Zufferey et al. (2010), Switzerland	Explores the process of patient's online health information searching before or after a	Ethical approval obtained. **Methodology:** Grounded theory. **Data collection method:** semi-structured interviews. Comparative analysis	Purposive sampling conducted. 27 patients with a variety of health conditions.	14 medical practices.	Findings reported that patients search online for health information to prepare for the medical consultation. Motivations as to why people were searching online were for acknowledgement, perspective and reduction of uncertainty.

	medical consultation.	adopted. MMAT = 5 (moderate-high).			
Chu et al. (2017), China	Explores individual's perceptions of online health information seeking and to understand their behaviours.	**Qualitative** Ethical approval obtained. **Methodology:** Phenomenology. **Data collection method:** Five focus groups. Thematic and in-depth analytic approaches used. MMAT = 4 (moderate).	49 participants aged 18 years or above and residing in Hong Kong.	Community	Older adults (55+) were less likely to use the internet to find health information. The main reasons for using the internet was because of limited time with the doctors, barriers to accessing professional health services and it was convenient. Although, the participants reported they limited trust in some online websites, and it caused some frustration and fear. However, regardless of the severity of the

					health issue, the internet was always the first source of information to be accessed.
Donnelly et al. (2008), UK	Explores the use of the internet and e-health amongst adults and their attitudes and reasons for using the internet for health information.	Ethical approval obtained. **Methodology:** Phenomenology. **Data collection method:** 4 focus groups with an open-ended schedule. Thematic analytic approach. MMAT = 4 (moderate).	16 participants recruited through quota convenience sampling.	Setting not stated.	Three themes developed from the data: decline in expert authority, pervasiveness of health information on the internet and empowerment. Participants tended to like the immediate benefits of e-health and felt empowered by increasing their knowledge however, they would be reluctant to lose face-to-face consultations with their GP over it.

El Sherif et al. (2018), Canada	To understand and describe the negative outcomes associated with online consumer health information in primary care from the viewpoint of consumers and practitioners.	Ethical approval obtained. **Methodology:** Two stage interpretive qualitative study. **Data collection method:** Social media survey and semi-structured interviews using a deductive-inductive thematic analysis. MMAT = 4	Purposive sampling strategy. Stage 1 (consumers): 148 completed surveys. Telephone interviews: 19 consumer participants. Stage 2 (health professionals): Interviews included 10 informants: 7 health practitioners (3	Primary care.	Negative outcomes of online consumer health information can occur at three levels: internal (e.g., increased worrying), interpersonal (e.g., patient clinician relationship tensions) and service related (e.g., postponing clinical encounters).

			family physicians, 2 nurses and 2 pharmacists) and 3 health librarians.		
Fiksdal et al. (2014), USA	Explores the perceptions of community members in relation to online health information seeking activities.	Ethical approval obtained. **Methodology: Data collection method:** three focus groups. Grounded theory approach to analysis. MMAT = 4 (moderate).	19 participants who are all residents of Olmsted County, Minnesota and are either mayo clinic patients, employees or have at least one family member who is a patient or employee.	Setting not stated.	Most patients found the internet to be a valuable tool to find information and it helped with their preparation for consultations. Patients viewed online health information seeking as a way to build the patient-doctor relationship.

Huisman et al. (2020), Belgium	Examined the role of online health information and its influence of the middle-aged and older adult patient-physician relationship.	Ethical consideration not reported. **Methodology:** qualitative interviews. **Data collection method:** semi-structured, in-depth qualitative interviews. MMAT = 4	40 participants recruited in the Flemish city of Ghent including adults between the ages of 50 and 64 (middle-aged) and 65 and 80 (older adults).	Local service centres and a Flemish association for the elderly.	Age and education level were found to be discriminating factors with whether individuals sought online health information or not. Older and lower educated individuals were more likely to not use the internet and rely on their doctor as their source of information. Whereas younger and highly educated individuals were more likely to use Doctor Google and obtain online health information.
Lee et al. (2014), Australia	Explores the navigational needs of the public when	Ethical approval obtained. **Methodology: Data collection method:**	Purposive sampling conducted. 17 participants in	Community - nine public pharmacies.	Participants wanted to be able to navigate the internet better to search for health information. Online health information

	searching for internet health information for self-management of chronic health conditions.	semi-structured face to face interviews. Thematic analysis undertaken. MMAT = 4 (moderate-high).	total. Participants were 18 years and over with at least one chronic health condition and used the internet to search for health information.		seeking was most commonly done after consultations with the health professional. Patients found online health information most commonly through search engines (Google). The study suggests more involvement by health professionals regarding online health information can benefit the patient.
Macias and McMillan. (2008), USA	Investigates how older adults use the internet to seek health information and health communication.	Ethical consideration not reported. **Methodology: Data collection method:** Focus groups. Corbin & Strauss (1990) method	31 participants recruited through snowballing techniques.	Community Centres.	Participants found that information that is easily accessible is not reliable or of high quality. Participants also did not trust advertising websites. They prefer collecting information from government

		of analysis. MMAT = 3 (moderate).			websites or educational institutions.
Mendes et al. (2017), Portugal	Explores the way young adults search for health information online and how they rank the sources of information by credibility and reliability.	Ethical consideration not reported. **Methodology:** Phenomenology. **Data collection method:** 15 qualitative interviews. Grounded theory approach undertaken. MMAT = 4 (moderate-high).	15 participants recruited from recruited from administrative staff at their routine follow-up appointments.	Epidemiology department of a medical school of a public Portuguese University.	The findings had shown that the participants found themselves committed to online health information but found healthcare professionals more resourceful. Although they found health information on the internet useful, they also felt it could be seen as unreliable.
Rupert et al. (2014), USA	Explores individual's use of information from online health	Ethical approval obtained. **Methodology:** Phenomenology. **Data collection method:**	89 Patients and caregivers who visited online health communities.	Online community.	Participants felt that online health communities provided more detailed information that the healthcare professional may not have had time to give.

	communities in medical consultations and examining how healthcare professionals react to this.	10 in-person and virtual focus groups. Thematic analytic approach. MMAT = 3 (moderate).			Patients and caregivers reported that they did not only want to learn about the medical aspects of their illness, but the emotional and logistical aspects as well. Although, it is suggested that online health communities can be used as a facilitator instead of a barrier for shared decision making between patients/caregivers and the healthcare professional.
Silver (2015), Canada	Explores patient's problems when going online to treat a health	Ethical approval obtained. **Methodology:** Exploratory study. **Data collection**	56 participants aged 50 years and over. Recruited through brochures that were	Community	36% of participants were concerned with non-physical harm that could happen from internet diagnosing and 29% had concerns with their anxiety.

	issue and identifies barriers when communicating this information with doctors.	**method:** semi-structured interviews about opinions and experiences of online health information seeking. Inductive content and thematic analytic approach to qualitative data. MMAT = 5 (high).	advertised in eight randomly selected neighbourhoods.		Participants felt sharig online health information with their doctors was embarrassing and not appropriate. Findings supported the need for doctors to try and guide the patients to high-quality online health information websites and in some cases, initiate the conversation about online health information seeking.
Sommerhalder et al. (2009), Switzerland	Analyses the benefits and difficulties of online health information from the patient and	Ethical approval requested but formal approval was not necessary for this study. **Methodology:** Grounded theory. **Data**	Patients and physicians from primary care and medical specialist practices. 32 patients and 20	Primary care and medical specialist practices. 104 randomly selected	Findings showed that physicians were happy to discuss online health information with patients during consultations although not all patients discussed this in

	physician perspective.	**collection method:** Semi-structured interviews. MMAT = 5 (high).	physicians. General practitioners (n=12) and specialists (n=8).	medical practices to recruit physicians.	consultations to avoid any conflicts and lack of time.
Stevenson et al. (2007), UK	Explored patient's views on the effects the internet has on the patient-doctor relationship.	Ethical approval obtained. **Methodology: Data collection method:** 8 disease specific focus groups. Subsequent analytic approach. MMAT = 5 (high).	34 adult patients. Adult patients with diabetes mellitus, hepatitis C or ischaemic heart disease.	Clinic and community settings.	The results showed that patients seeking health information online is not to disrupt the balance of power or roles in the consultation but instead used as an additional source for patients. Doctors should not feel challenged by patients bringing online health information to consultations and should instead see it as the patient trying to work alongside

					the doctor with hope for them to respond positively.
Townsend et al. (2015), Canada	Explores the influence of different types of eHealth use and how internet health information can impact the patient-HCP relationship.	Ethical considerations not reported. **Methodology:** Grounded theory. **Data collection method:** Focus group discussions recruited through online arthritis sites, web and social media sites such as Facebook and Twitter. An iterative, thematic analysis approach was	18 patients with arthritis and co-conditions, along with 14 healthcare professionals (physical and occupational therapists, rheumatology nurse, laboratory technician, rheumatology fellows, physicians and rehabilitation providers	Community centres, health care centres or participants work.	Patients had a tendency to go online for information about diagnosis and to find others experiencing similar symptoms. Health related internet information can support patient decision making and empowerment however, can also cause tension in the relationship – such as time constraints or difference in opinion. Healthcare professionals have learned techniques to handle negotiation in the consultation and to avoid conflicts.

		undertaken. MMAT = 5 (high).			

Appendix 6: Quantitative data extraction table

Author/Year/Country	Aims of study	Methods & Quality	Participants	Settings	Key findings
Audrain-Pontevia and Menvielle. (2018), **Canada**	Examined how online health communities impacts the patient-physician relationship.	Ethical considerations not reported. **Methodology:** Online survey. **Data collection method:** Online survey with randomised measurement items. Data analysed using	328 responses collected from online patient groups in Canada in 2016.	Online patient groups.	Online social support has a positive influence on patient empowerment and participation in their healthcare appointments. Online empowerment gained from participating in online health communities are critical to influencing patient participation within consultations and patient commitment to the relationship with the physician.

		structural equation modelling. MMAT = 3 (moderate).			
Barnoy et al. (2008), Israel	Examined nurse's attitudes towards internet informed patients and elements that may influence their attitude.	Ethical approval obtained. **Methodology:** Survey. **Data collection method:** Questionnaire. Regression analysis conducted. MMAT = 2 (low).	110 hospital nurses (32 practical nurses, 35 registered nurses and 43 with a BA nursing degree). Aged between 21-49 years.	Hospital nurses	Nurses with more experience had a better attitude towards online health information than those with less experience. The findings showed that the more computer literate nurses are, the more positive their attitudes are about patients presenting with internet health information.

Barnoy et al. (2011), Israel	Explored nurse's reactions to online health information that was retrieved from sources of different credibility and the link between self-epistemic authority and the reactions.	Ethical approval obtained. **Methodology:** Survey. **Data collection method:** Questionnaire. T-tests were used to carry out analysis. MMAT = 2 (low).	(N=101) female hospital staff nurses	Tel Aviv University OR hospital	Nurses that had obtained an academic degree, had a more positive attitude to internet health information seeking as opposed to nurses who did not have an academic degree. Nurse's reactions to different sources of internet information vary on their education and level of self-epistemic authority.
Bartlett and Coulson. (2011), UK	Explores the effects that online support groups may have on the patient-	Ethical considerations not reported. **Methodology**: Survey **Data**	246 participants recruited from 33 chronic illness online	Chronic illness online support groups.	82.2% of participants had discussed information they found online with their health professional and 74.2% were satisfied with how the health professional responded. Although,

	health care professional relationship and patient empowerment.	**collection method:** Online questionnaire. Descriptive statistics and binary and multiple logistic regressions used for analysis. MMAT = 2 (low).	support groups.		60.3% felt being a member of an online support group has affected their relationship with health professionals.
Bell et al. (2011), USA	Examines the reasons why patients seek health information online and the predictors and prevalence of	Ethical approval obtained. **Methodology:** Online survey. **Data collection method:** Questionnaire. Descriptive statistics and	Non-random convenience sample of 274 respondents. Recruited from an online community -	Online health community.	60.8% went online to search for information post medical visit. Going online was identified with issues with trust (P=.002) and increased worrying (P=.049). The most common reason for these searches were for being curious (71%) and also not being satisfied

	online health information seeking after a medical appointment.	logistic regression analysis. MMAT = 2 (low).	'Daily Strength'.		with the physician's behaviour (32%).
Giveon et al. (2009), Israel	Evaluate the reactions of primary care physician's reactions in response to internet informed patients and to assess the influence of physician's	**Quantitative** Ethical considerations not reported. Cross-sectional design. **Methodology:** Survey. **Data collection method:** 17 item questionnaires. SPSS-PC software	Convenience sample of 118 primary care physicians from rosters of Clalit Health Services.	Primary care clinics and medical education course at Tel Aviv University.	66.7% of physicians were satisfied with the quality of online health information that their patients brought. 88.7% were content with their relationships with patients and with the knowledge they collected from their patients and their use of online information. Most physicians found it favourable for patients to bring information from the internet to consultations and demographic

	personal and demographic characteristics on their satisfaction with e-patients.	used and chi-square. MMAT = 3 (moderate).			variables did not affect physician behaviour with e-patients.
Haluza et al. (2017), Austria	Explores the public perceptions of online health information seeking and the impact this has on the doctor-patient relationship.	Ethical approval obtained. Cross sectional study **Methodology:** Online survey. **Data collection method:** Questionnaire. Descriptive statistics to report quantitative data.	Convenience sample of 562 participants.	Setting not stated.	Digital immigrants (38.9%) found data exchange to be more acceptable than digital natives (30.8%). 55.2% reported visiting online health websites after a doctor's consultation – digital natives more likely (59.7% vs. 49.8%). Overall, the internet was the most used health information source amongst digital generations although, doctors still remained the

		MMAT = 2 (moderate).			most preferred source of health information.
Imes et al. (2008), USA	Explores the possibilities of why patients may resist discussing online health information with their healthcare providers.	Ethical approval obtained. **Methodology:** Online survey over a 6-month period. **Data collection method:** 11 closed-ended items, 4 open-ended itemed and demographic information questionnaires. Reliability measured using Cohen's kappa.	714 participants recruited from internet health message boards.	Online setting.	20.2% refrained from sharing online health information with their healthcare provider as they reported they were searching for their own personal benefit and a further 10% didn't share as they did not trust the resource. 13% did not want to step on the provider's 'turf' therefore, did not disclose their found information. 8.2% felt embarrassed to show it and 14.4% felt they would be dismissed or that the healthcare provider would be uninterested in their findings.

		MMAT= 3 (moderate).			
Lu et al. (2018), China	To understand the effects of the quality of online health information on patient compliance.	Ethical considerations not reported. **Methodology:** Cross-sectional survey. **Data collection method:** Web-based survey. MMAT = 4 (moderate).	336 participants.	Online survey.	Patients reported internet health information quality playing a stronger role than the source in impacting their trust and compliance with physicians. Patient compliance could be improved if there is a focus on strengthening the management of online health information quality.
Ohana and Barnoy. (2019), Israel	Examined patient's information	Ethical approval obtained.	184 e-patients, 52 nurses and 48 physicians.	Hospital discharge.	E-patients felt comfortable sharing their online findings with HCP's however, the internet did not

	needs and the patient-HCP relationship from both patient and HCP perceptions.	**Methodology:** Cross-sectional study. **Data collection method:** Cross-sectional questionnaire. MMAT = 3 (moderate).			replace the HCP. Online health information did not impact the patient-caregiver relationship.
Russ et al. (2011), Israel	Examined internet use for health information seeking by primary care	Ethical considerations not reported. **Methodology:** Cross-sectional survey. **Data**	Convenience sample of 138 patients visiting primary care clinics.	10 primary care clinics.	89% had internet access and 41% used the internet as a source for health information. Although, most patients did not share the information they found with their doctor (81%). Although, those who

	patients and their perceptions of effects internet use may have on their relationship with the doctor.	**collection method:** Questionnaire. Analysed using EPI-INFO software and tested using chi-square and t-tests. MMAT= 4 (moderate-high).			did believed it had a positive impact on their relationship with the doctor (87%). 77.9% of patients would be interested in doctors referring them to quality health information websites.
Singh and Banerjee. (2019), India	To understand the patient opinion of the impact of the internet on the doctor-patient relationship.	Ethical approval obtained. **Methodology:** Cross-sectional study. **Data collection method:** Close-ended survey.	709 participants (307 from urban field practice area and 402 from the rural field practice area).	Outpatient departments of rural and urban health centres.	Urban patients (79.48%) were more likely to use the internet for health information compared to rural patients (28.11%). Users of the internet (51.26%) believed that online health information seeking would improve the doctor-patient relationship, compared to nonusers (17.05%).

		MMAT = 3 (moderate).			
Zhang et al. (2021), China	To understand the impact of treatment-related online health information seeking behaviour on the patient-physician relationship.	Ethical approval obtained. **Methodology:** Questionnaire. **Data collection method:** Web-based questionnaire survey. MMAT = 4 (moderate).	336 Chinese participants who received treatment in the past month of the study and searched the internet for health information.	Online survey.	Patients having access to treatment related health information online, will not have a negative impact on the patient-physician relationship. Encouraging patients to seek treatment online health information, can increase and improve patient compliance.

Appendix 7: Mixed method data extraction table

Author/Year/Country	Aims of study	Methods & Quality	Participants	Settings	Key findings
Hay et al. (2008), USA	Explores the online information seeking of multiple sclerosis (MS) patients and their reasons for doing so, and the importance of physician-patient communication about this information.	Ethical approval obtained. Semi-structured interviews, before and after appointments for patients presenting at the clinic for the first time. 3-item post appointment questionnaire on physician's satisfaction with appointment. MMAT = 3 (moderate).	(N=61) participants. 79% female and 21% male.	MS clinic.	82% of participants collected online health information before their first appointment and 36% discussed the information with their physician. A reason for not showing the physician the information was because of wariness of health care and potentially leading to non-adherence.

Appendix 8: Socio-demographic table

Author/Year/Country	**No. of participants**	**Types of participants**	**Gender**	**Age**	**Ethnicity**	**Socioeconomic status**
Ahluwalia et al (2010), UK	11 general practitioners	General practitioners: five partners, three locums and three salaried doctors.	Female (n=6) Male = (n=5)	Age not reported.	White (n=7) Asian (n=3) Chinese (n=1)	Socioeconomic status not reported.
Audrain-Pontevia and Menvielle. (2018), Canada	328 respondents.	Online patient groups in Canada.	Male (n=136) Female (n=189)	18-34 years (n=121) 35-49 years (n=106) 50-65 (n=87) 65 years and above (n=14)	Ethnicity not described.	Education: Highschool graduate (n=77) College graduate (n=146) Graduate college or higher (n=69) Employment: Employed (n=258) Not employed (n=70)

Barnoy et al (2008), Israel	110 hospital nurses	Practical nurses (n=32), registered nurses (n=35), academically trained nurses (n=43).	Female (n=101) Male (n= 9).	Age range from 21-49 years. Mean age = 30.83.	Immigrants from the former Soviet Union = 60%, native born Israelis = 33%, other countries = 7%.	Socioeconomic status not reported.
Barnoy et al (2011), Israel	101 female hospital staff nurses.	Registered nurses with bachelor's degree in nursing (n=36). Registered nurses without academic degree (n=65).	Female (n=101) Male (n= 0)	Mean age = 30.9	Birth place: Israel (n=17), Former Soviet Union (n=29), Asia (n=4), Europe (n=3)	Socioeconomic status not reported.

Bartlett & Coulson (2011), UK	246	Chronic illness online support groups.	Females (n= 174) Males (n=72)	Age range from 21-100, Mean age = 50.41	Ethnicity not described.	Socioeconomic status not reported.
Bell et al. (2011), USA	274	Internet support community members.	Female (n=227) Male (n=47)	18-29 (n=45) 30-39 (n=49) 40-49 (n=64) 50-59 (n=77) 60-69 (n=35) ≥70 (n=4)	White (n=256) Other (n=18)	Education: High school graduate/or less (n=45), A.A./tech degree or some college (n=127), college graduate (n=102). Income: Low- ≤$40,000 (n=110), Moderate - >$40,000 to ≤$80,000 (n=92), High >$80,000 (n=62), refused to answer (n=10).

Benetoli et al (2018), Australia	36	Patients with chronic conditions and on medications who have used social media for health reasons.	Female (n=17) Male (n=19)	Age range= 27-71 years Mean age= 47.3 years.	Birth country: Australia (n=26) England (n=2) New Zealand (n=2) Other (n=6)	Education: < high school (n=3), high school (n=11), college or technical education (n=6), undergraduate (n=12), postgraduate (n=2), missing data (n=2). Employment: Full time (n=18), part time (n=9), home duties (n=3), retired (n=2), unemployed (n=4).
Bowes et al (2012), UK	26	Participants who reported online health information to their GP.	Female (n=16) Male (n=10)	Participants all over 18 years old.	White (n=19) Other (n=7)	Education: Degree level or higher (n=18).
Caiata-Zufferey & Schulz (2012), Switzerland	17 physicians	Physicians from primary care and medical specialist	Female (n=3) Male (n=14)	Aged between 40 and 64 years.	Ethnicity not described.	Socioeconomic status not reported.

		practices. General practitioners (n=5), gynaecologists (n=3), orthopaedic surgeons (n=2), urologists (n=2), oncologists (n=2), allergist (n=1), endocrinologist (n=1), rheumatologist (n=1).		Mean age = 52.		
Caiata-Zufferey et al. (2010), Switzerland	27	Patients that had search for health information online that related to a	Female (n=16) Male (n=11)	Age ranges from 21-69 years. Mean	Ethnicity not described.	Education: Completed secondary school (n=2) Certificate of apprenticeship

		problem they discussed in the medical encounter.		age was 43 years.		(n=12) Completed high school or equivalent (n=5) University degree (n=8) Work: Paid job (n=18) Homemakers (n=7) Retired (n=1) Unemployed (n=1)
Chu et al. (2017), China	49	Not described.	Female (n=23) Male (n=26)	18-24 (n=9) 25-34 (n=8) 35-44 (n=8) 45-54 (n=6) 55-64 (n=8) 65+ (n=8)	Ethnicity not described.	Education: Primary or below (n=2), secondary (n=14), tertiary or above (n=31). Monthly income: <10,000 (n=7), 10,000-19,999 (n=7), 20,000-29,999 (n=8),

						30,000-39,999 (n=4), 40,000+ (n=12).
Donnelly et al. (2008), UK	16	Not described.	Female (n=8) Male (n=8)	Age range from 19-62 years. Mean age = 37.5 years.	All participants white British.	Socioeconomic status not reported.
El Sherif et al. (2018), Canada	148 survey respondents, 19 telephone interview participants and 10 face-to-face interview participants.	Stage 1 (consumers): 148 completed surveys. Telephone interviews: 19 consumer participants. Stage 2 (health professionals): Interviews included	Gender only reported in stage 1 (n=19): Female (n=15) Male (n=4)	Most respondents in stage 1 (n=19) were in the age range of 18-24 years (n=15) 25-34 (n=3) 45-54 (n=1).	Ethnicity not described.	Socio-economic status not reported.

		10 informants: 7 health practitioners (3 family physicians, 2 nurses and 2 pharmacists) and 3 health librarians.				
Fiksdal et al. (2014), USA	19	Mayo clinic patients, employees and family visitors.	Female (n=14) Male (n=5)	Mean age = 43.26 years	White (n=15) Black or African American (n=0) Asian (n=4)	Education: High school or GED (n=0), community or junior college (n=3), four-year college (n=3), graduate school (n=13). Household income: $15,000-$35,000 (n=2), $35,001-$55,000 (n=9), $55,001-$75,000 (n=4),

						$75,001-$100,000 (n=0), over $100,000 (n=1), prefer not to say (n=3).
Giveon et al (2009), Israel	118 physicians	Primary care physicians, board certified specialists in family medicine, general practitioners without board certification and final year family medicine residents working in own practice.	Female= (n=39) Male= (n=79)	Mean age = 49 years	Place of birth: Israel (n=71) Eastern Europe (n=33) Other (n=14)	Socioeconomic status not reported.

Haluza et al (2017), Austria	562	Public	Female (n=331) Male (n=231)	Mean age was 36.9.	Vienna	Education: Primary (n=90) Secondary (n=191) Tertiary (n=281) Healthcare professional (n=243), non-healthcare professional (n=319).
Hay et al. (2008), USA	61	Patients attending an MS clinic for the first time.	Female (n=49) Male (n=12)	0-30 (n=11) 30-50 (n=33) >50 (n=16)	Ethnicity not described.	Education: ≤$40,000 (n=9), $40,000-$100,000 (n=29), >$100,000 (n=21).
Huisman et al. (2020), Belgium	40 participants.	Flemish middle-aged adults between the ages of 50 and 80 years.	Female (n=22) Male (n=18)	All participants aged between 50 and 80 years. Average age of 64.9 years.	Ethnicity not described.	Education: Higher education (university degree) - 35% Middle education (higher secondary) - 37.5% Lower education (lower secondary) – 27.5%.

Imes et al (2008), USA	714	Participants recruited from internet health message boards.	Female= 89.3% Male= 10.7%	Mean age = 43 years.	Majority of participants lived in Vienna.	Median range for household income = $40,000-59,000. Lived in urban areas = 58%, suburban areas = 18%, small towns = 16%, rural areas = 8%
Lee et al. (2014), Australia	17	Patients with chronic health conditions.	Female (n=9) Male (n=8)	Age ranges from 19-85 years. Most common age category between 50-60 years.	Ethnicity not described.	University students (n=3) Workforce (n=8) Retirees (n=6).
Lu et al. (2018), China	336 participants.	Not described.	Male (n=156) Female (n=180)	20 years and under (n=22) 20-29 (n=83) 30-39 (n=107) 40-49 (n=59)	Ethnicity not described.	Resident status: Urban: (n=184) Rural: (n=152) Education: Junior middle school (n=31)

				50-59 (n=47) 60 years and over (n=18)		High school (n=96) Junior college (n=68) Bachelor's degree (n=127) Master's degree (n=9) Doctor's degree (n=5) Job: Employed (n=276) Students (n=38) Retired (n=22)
Macias and McMillan. (2008), USA	31	Participants age 60 or over and use the internet for more than just emails.	Female (n=15) Male (n=16)	Age range from 63-83 years. Mean age = 72.80.	Ethnicity not described.	Socioeconomic status not reported.
Mendes et al. (2017), Portugal	15	Health individuals born in 1990 with no diagnosis or at	Female (n=8) Male (n=7)	Age not reported.	All participants were white European.	All lived in metropolitan area of northern Portuguese city. All university students except

		risk of a medical condition.				one who completed 6 years of high school.
Ohana and Barnoy. (2019), Israel	100 HCP's and 184 e-patients.	100 HCP's (nurses and physicians) and 184 e-patients living with a chronic disease.	Patients: Male (22%) Female (78%) HCP's: Male (81%) Female (12%)	Average age of the patients was 40. Average age of the physicians was 43 and the nurses was 44.	Ethnicity not described.	Socio-demographic status not reported.
Rupert et al (2014), USA	89	Patients/caregivers who use online health community groups.	Female (n=58) Male (n=31)	18-24 (n= 6) 25-34 (n= 16) 35-44 (n= 20) 45-54 (n= 27) 55-64 (n=16) 65-74 (n= 4)	Caucasian (n=62), African American (n=17), Hispanic	< High school (n=1), high school (n=3), some college or technical school (n=22), college graduate (n=39), some graduate school (n=6),

					(n=2), Asian (n=2), Hawaiian or Pacific Islander (n=2), Other (n=4).	graduate school degree (n=17).
Russ et al (2011), Israel	138	Patients visiting the selected 10 primary care clinics.	Female (n=82) Male (n=53)	Mean age = 38.7 years.	Israel	Education: Elementary (n=5) High school (n=34) University (n=96) Income: < national average (n=21) Average (n=78) > average (n=31)
Silver (2015), Canada	56	Participants over 50 years old, have regular contact with primary care	Female (n=30) Male (n=26)	Mean age = 69	Born in Canada (n=32) Other (n= 24)	Education: <High school (n=7), completed high school (n=11), college/university

		physician or general practitioner and use the internet regularly for health-related issues.				(n=14), graduate school (n=24). Income: Income > Canadian $60,000 (n=26).
Singh and Banerjee. (2019), India	709 participants.	709 newly registered patients in the outpatient department of rural and urban health centres.	Male (n=405) Female (n=304).	The mean age of participants was 35.2 years.	Ethnicity not described.	Urban field practice areas (n=307) Rural field practice areas (n=402)
Sommerhalder et al (2009), Switzerland	Patients (n=32) Physicians	Patients and physicians from primary care and medical specialist	Patients: Female (n=12) Male (n=20)	Age range from 19-79. Mean age= 49	Ethnicity not described.	< 12 years of education (n=17) High school (n=13).

	(n=20) Total: (n=52)	practices. General practitioners (n=12) and specialists (n=8).	Physicians: Female (n=4) Male (n=16) Female patients= 12			
Stevenson et al. (2007), UK	34	Patients with diabetes mellitus, ischaemic heart disease or hepatitis C.	Female (n=12) Male (n=22)	30-39 (n=3) 40-49 (n=4) 50-59 (n=7) 60-69 (n=16) 70-79 (n=4)	White British (n=26), White European (non-British origin) (n=5), Asian or British Asian (n=2), Black or Black British (n=1).	Education: School leaver (n=8), A levels or equivalent (n=7), Degree, HND or similar (n=17), not disclosed (n=2). Employed (n=8), economically active (n=26).

Townsend et al (2015), Canada	18 patients and 14 healthcare professionals.	Patients with arthritis and at least one other condition. HCPs included physical and occupational therapists, rheumatology nurse, laboratory technician, rheumatology fellows and physicians and rehabilitation providers.	Patients: Female (n=16) Male (n=2) Healthcare professionals: Female (n=11) Male (n=3)	Patients: between 30-70 years old. Healthcare professionals: between 30-60 years old.	Majority Caucasian.	Majority was middle-class and Caucasian.
Zhang et al. (2021), China	336 participants.	336 Chinese participants who	Male (n=156)	< 20 (n=22) 20-29 (n=83)	Chinese participants.	Resident status: Urban (n=184)

		received treatment in the past month of the study and searched the internet for health information.	Female (n=180)	30-39 (n=107) 40-49 (n=59) 50-59 (n=47) >60 (n=18)		Rural (n=152) Education: Junior middle school (n=31) Highschool (n=96) Junior college (n=68) Bachelor’s degree (n=127) Master’s degree (n=9) Doctor’s degree (n=5)

Appendix 9: Mixed methods appraisal tool - quality appraisal

Citation	**Screening questions**		**QUALITATIVE STUDIES**					**Comments**	**MMAT score and overall quality**
	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?		
Ahluwalia et al (2010)	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	A qualitative descriptive approach using semi-structured interviews was adopted. The approach was	3 (moderate)

								not specified in the study. The framework approach to analysis was used. The results were reported adequately and include quotes to justify themes. There are clear links between data sources, collection, analysis and interpretation.	
Benetoli et el (2018)	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	A qualitative descriptive approach using focus groups was undertaken and appropriate for this study. The type of qualitative approach was not specified. Thematic analysis was used with an	4 (moderate -high)

								inductive approach. The results are reported adequately and include quotes to justify themes. There are clear links between data sources, collection, analysis and interpretation. Focus groups were the most appropriate method of data collection so the face-to-face reactions could be observed, and a discussion could be formed.	
Bowes et al (2012)	Yes	Yes	Yes	No	Can't tell	Yes	Yes	A qualitative description study using semi-structured interviews with	3 (moderate)

								either a face-to-face or telephone approach. Interviews were audio recorded. This presented the patients experiences. An inductive approach was used for analysis. There are several in-depth research questions proposed and focus groups or a more open method of data collection may have been more appropriate to accurately represent the patient’s experiences. Quotes are provided to justify the themes. There	

								are clear links between data sources, collection, analysis and interpretation.	
Caiata-Zufferey et al (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Semi-structured interviews were conducted, and this was an appropriate method to meet proposed research questions. A grounded theory approach was undertaken. Quotes are provided to justify themes and there are clear links between data sources, collection, analysis and interpretation.	5 (Moderate -high)

Caiata-Zufferey and Schulz (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Semi-structured interviews used and were suitable to answer the research questions opposed. A grounded theory approach was adopted and was appropriate for the topic. Constant comparative method with an inductive approach was used for analysis and cooperates well with grounded theory. Quotes were provided in results to justify the themes and results are reported adequately. There is a clear link	5 (High)

								between data sources, collection and interpretation.	
Chu et al (2017)	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Qualitative approach was not specified. Focus groups were used for data collection which cooperated well with the research questions. Thematic analysis and an in-depth analysis were adopted. Quotes are provided for justification of themes and there is a clear link between data sources, collection,	4 (Moderate)

								analysis and interpretation.	
Donnelly et al (2008)	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Qualitative approach not specified. Focus groups were digitally recorded and were used alongside a thematic analysis approach. The findings were adequately derived from the data and quotes were reported to justify themes. There is a clear link between data sources, collection, analysis and interpretation.	4 (Moderate)

El Sherif et al (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Two stage interpretive qualitative study. Social media survey and semi-structured interviews were conducted which was appropriate to meet the proposed research questions. Quotes are provided to justify themes and there are clear links between data sources, collection, analysis and interpretation.	4 (Moderate-high)
Fiksdal et al (2014)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Focus groups with 4-5 participants per group and semi-structured moderator guide. A grounded theory	4 (Moderate)

								approach but not described in sufficient detail. Limited generalisability. Quotes were also provided to justify themes. There are clear links between data sources, collection, analysis and interpretation.	
Huisman et al (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Semi-structured in-depth interviews with 40 participants which was appropriate to meet the research questions. Quotes are provided to justify themes and there are clear	4 (Moderate -high)

								links between data sources, collection, analysis and interpretation.	
Lee et al (2014)	Yes	Yes	No	Yes	Yes	Yes	Yes	Qualitative approach no described. Semi-structured interviews were conducted which was appropriate to meet the proposed research questions. A thematic analysis approach was adopted with two stages - a data-driven approach and a theory-driven approach. Quotes are provided to justify themes and there are clear	4 (Moderate -high)

								links between data sources, collection, analysis and interpretation.	
Macias and McMillan (2008)	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Qualitative approach not specified. Focus groups were audio-taped. Open coding followed by axial coding and then selective coding was used. Quotes are provided to justify themes and there is a clear link between data sources, collection, analysis and interpretation.	3 (Moderate)

Mendes et al (2017)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Exploratory study using qualitative interviews were conducted alongside grounded theory methods of coding and constant comparison. Quotes are provided to justify themes and there are clear links between data sources, collection, analysis and interpretation.	4 (Moderate-high)
Rupert et al (2014)	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes	Qualitative approach not described. Focus groups conducted with an adopted three-tier coding scheme for analysis which was inductive. Quotes are	3 (Moderate)

								provided to justify themes and there are clear links between data sources, collection, analysis and interpretation.	
Silver (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	This qualitative exploratory study used semi-structured interviews for data collection methods. An inductive content analysis derived from grounded theory approach was used followed by thematic analysis. Quotes are provided to justify themes and there are clear links	5 (High)

								between data sources, collection, analysis and interpretation.	
Sommerhalder et al (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Semi-structured interviews were conducted following the core principles of grounded theory. Quotes are provided to justify themes and there are clear links between data sources, collection, analysis and interpretation.	5 (High)
Stevenson et al (2007)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Focus groups were used which is appropriate for the proposed research questions. An initial coding	5 (High)

								frame was used for qualitative analysis. Quotes are provided to justify themes and there are clear links between data sources, collection, analysis and interpretation.	
Townsend et al (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Grounded theory approach. Focus group qualitative study with an iterative, thematic analytic approach using constant comparative methods - integrates well with grounded theory. Quotes are provided to	5 (High)

								justify themes and there are clear links between data sources, collection, analysis and interpretation.	

Citation	**Screening questions**		**QUANTITATIVE STUDIES**					**Comments**	**MMAT score and overall quality**
	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the sampling strategy relevant to answer the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?		

Audrain-Pontevia and Menvielle (2018)	Yes	Yes	Yes	No	Yes	Yes	Yes	The sampling strategy was not identified, and the sample consisted of responses collected from online patient groups which meant the results cannot be generalised beyond this group. The survey was an appropriate tool and a Harman's one-factor analysis was run which indicated the absence of common method bias. The data were analysed using structural equation modelling which was deemed appropriate.	3 (Moderate)
Barnoy et al (2008)	Yes	Yes	Can't tell	No	Yes	Can't tell	Yes	The sampling strategy used was convenience sampling,	2 (Low)

								not generalisable. There is no target population stated. The questionnaire was pre-tested for validity and reliability. There is nothing reported about the non-response rate. The statistical analysis (t-test), was appropriate for the research questions.	
Barnoy et al (2011)	Yes	Yes	Can’t tell	Can’t tell	Yes	Can’t tell	Yes	The way the sample was selected was adequate however, there was no sampling strategy identified. There was no previous target population stated and also no explanation of the non-	2 (Low)

								response rate. Measurements were appropriate and the questionnaire was validated. Data analysis was conducted with t-tests which is appropriate for the proposed research questions.	
Bartlett and Coulson (2011)	Yes	Yes	Can’t tell	Can’t tell	Yes	Can’t tell	Yes	The sampling strategy was not identified, and the sample consisted of existing online support group members which meant the results cannot be generalised beyond this group. The questionnaire	2 (Low)

								was an appropriate tool and there was no report of nonresponse bias. The statistical analysis of multiple and binary logistic regressions was appropriate.	
Bell et al (2011)	Yes	Yes	No	No	Yes	Can't tell	Yes	The sampling strategy was non-random convenience sampling of online support group members and was disproportionate of the types of people who participate in online health forums - white women. Survey was appropriate to research questions and	2 (Low)

								data analysis used logistic regression analysis.	
Giveon et al (2009)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Convenience sampling was used, and the sample was viewed as not large enough to represent the whole population although was originally proposed to as there was a random selection of a representative sample. The measurements were appropriate being a questionnaire that was piloted for reliability and validity. The study included the non-response	3 (Moderate)

								rate and had an overall response rate of 85%. Chi square testing was used.	
Haluza et al (2017)	Yes	Yes	No	No	Yes	Can't tell	Yes	Nonprobability convenience sampling used. The results were not generalisable to the whole population as the scope of study was restricted to a small nonprobability convenience sample of Austrian citizens. Descriptive statistics and binary logistic regression analysis were used. The questionnaire was piloted.	2 (Moderate)

Imes et al (2008)	Yes	Yes	Yes	No	Yes	Can’t tell	Yes	Convenience sampling was used although the sample may not be representative of the whole population, not generalisable. Those recruited were from the internet and were willing to take time to participate - women and whites were over sampled in this study. Reliability was measured using Cohen's kappa.	3 (Moderate)
Lu et al (2018)	Yes	Yes	Yes	No	Yes	Yes	Yes	The sampling strategy was not identified, and the sample consisted of 336 participants completing a cross-sectional, web-based	4 (Moderate)

								survey. The sample may not be representative to the whole population. IBM's SPSS 22.0 and Amos 22.0 were used which was reported to achieve efficient and unbiased analysis. Confirmative factor analysis and structural equation modelling was used to test the hypothesis.	
Ohana and Barnoy (2019)	Yes	Yes	Yes	No	Yes	Can't tell	Yes	The sampling strategy was not identified, and the sample consisted of 184 e-patients, 52 nurses and 48 physicians who completed	3 (Moderate)

								a cross-sectional questionnaire. T tests for independent samples were performed and paired t tests were performed to examine difference between items in the patient's questionnaire. Multiple linear regressions were conducted.	
Russ et al (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Convenience sampling was used but may represent the population better if there was a bigger sample size. The questionnaire was pre-tested with 7 patients to ensure it was	4 (Moderate -high)

								understandable and and easy to complete. Chi squares and t-tests were used for analysis. There was 69% response rate making the sample size, 138.	
Singh and Banerjee (2019)	Yes	Yes	Yes	Can’t tell	Yes	No	Yes	The sampling strategy was not stated, and the sample consisted of 709 participants who completed a cross-sectional, close ended survey. No tests were conducted to eliminate social desirability bias. The measurements were	3 (Moderate)

								appropriate and categorical data were summarised by percentages with 95% confidence intervals while quantitative data were summarised by mean and standard deviation.	
Zhang et al (2021)	Yes	Yes	Yes	No	Yes	No	Yes	Questionnaire method was appropriate however sample size was not representative of the whole population. Variables were measured using previously validated multiple-item scales. The questionnaire validity rate	4 (Moderate)

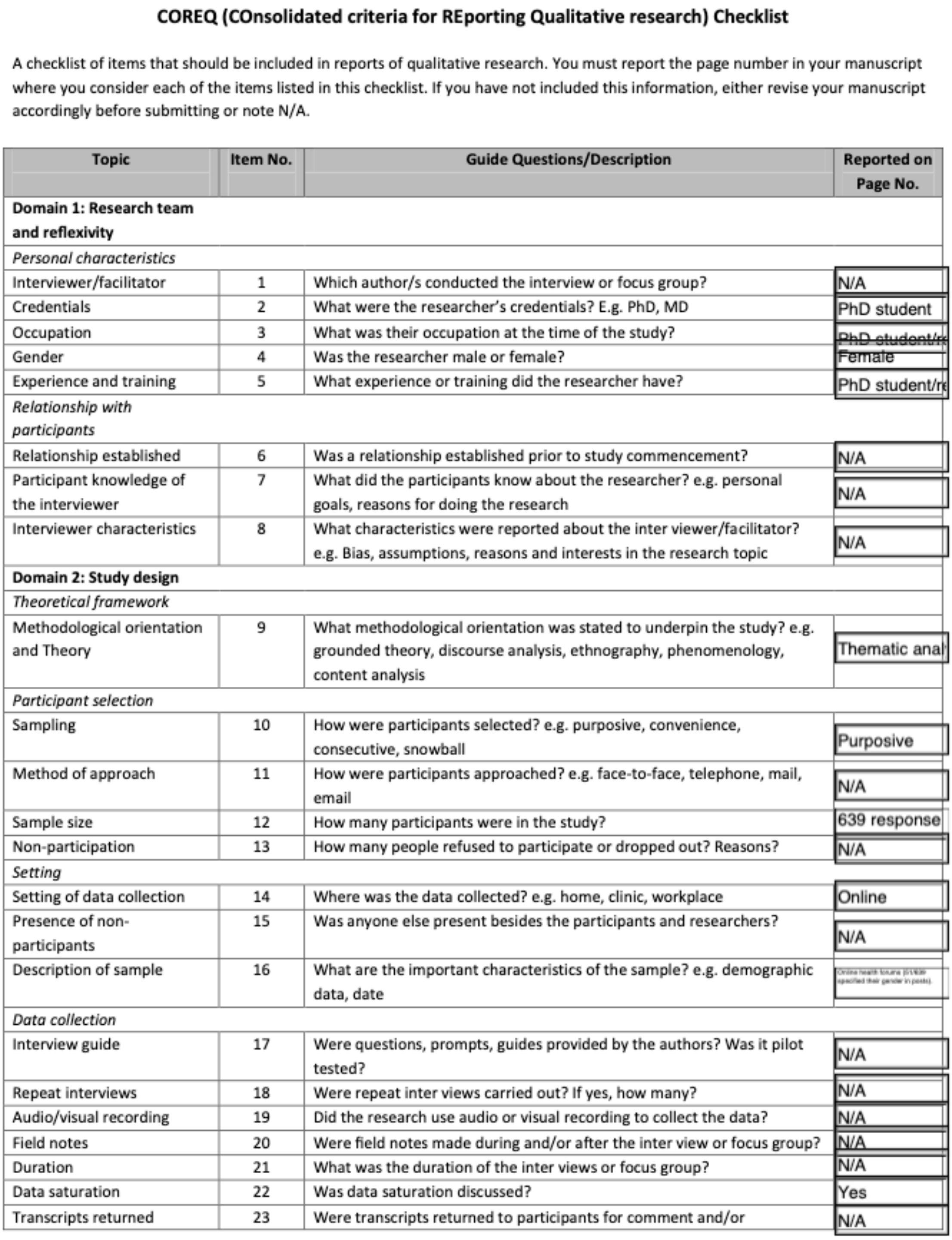
								was 89.6% and reliability and validity were acceptable. Confirmatory factor analysis and structural equation modelling were used to test the hypotheses and develop the research model.	

Citation	**Screening questions**		**MIXED METHODS STUDIES**					**Comments**	**MMAT score and overall quality**
	Are there clear research questions?	Do the collected data allow to address the	Is there an adequate rationale for using a mixed methods	Are the different components of the study effectivel	Are the outputs of the integration of qualitati	Are divergences and inconsistencies between	Do the different components of the study adhere to the quality		

		research questions?	design to address the research question?	y integrated to answer the research question?	ve and quantitative components adequately interpreted?	quantitative and qualitative results adequately addressed?	criteria of each tradition of the methods involved?		
Hay et al (2008)	Yes	Yes	Yes	No	No	Yes	Yes	Observational mixed methods study, using a survey and interviews pre and post appointments. The justification of using mixed methods is clear as the research question asks which patients are most	3 (Low-moderate)

								likely to go online (quantitative), and why the go online (qualitative). The quantitative and qualitative results were not integrated adequately and there is no section explaining the integration. The qualitative analysis seems appropriate but there is no specific methodology mentioned – could have been described in more detail. The results are merged adequately together and clearly presents the qualitative and quantitative results.	

Appendix 10: The Consolidated Criteria for Reporting Qualitative Research (COREQ) (online health forum studies)



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

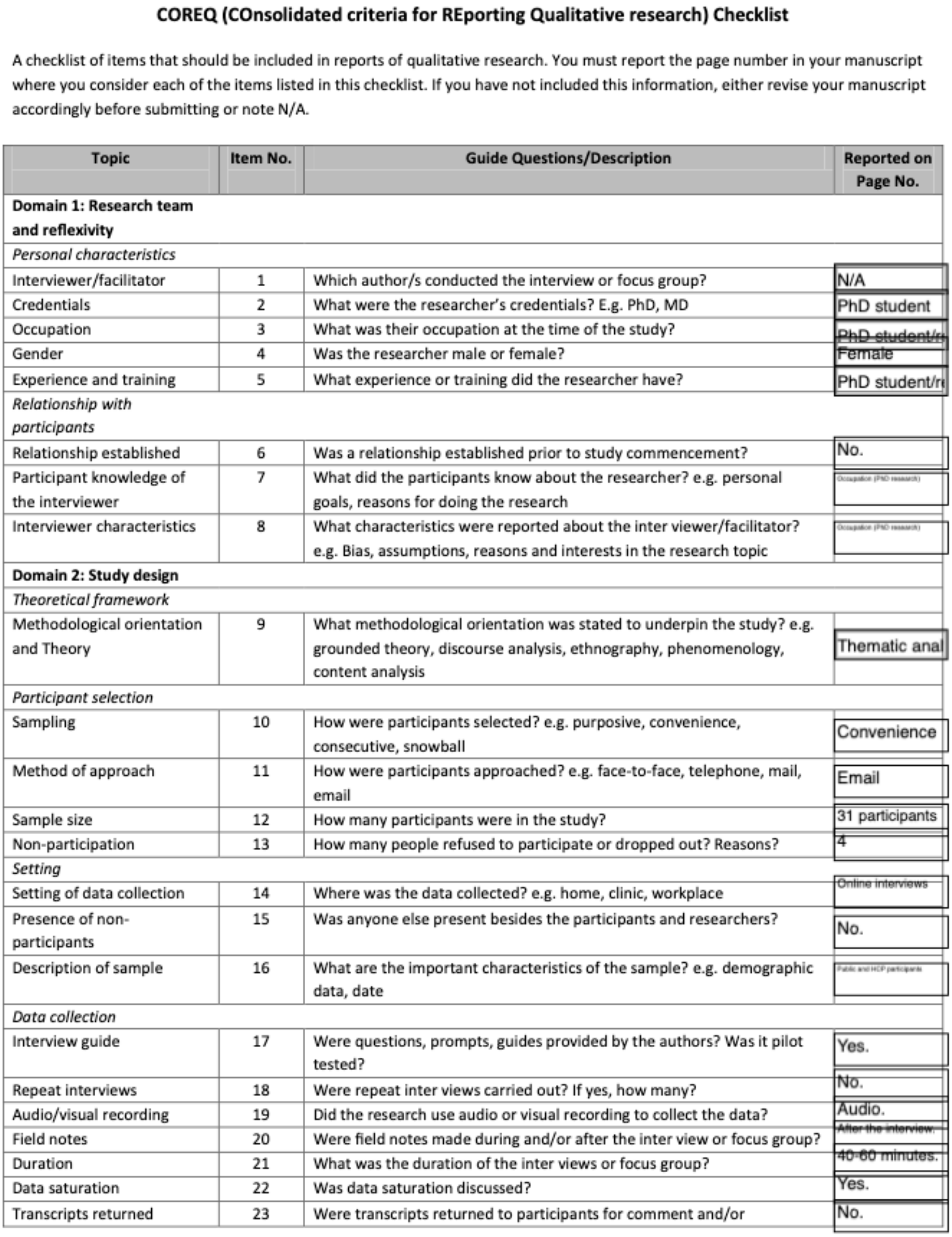
Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	N/A
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	PhD student
Occupation	3	What was their occupation at the time of the study?	PhD student/r
Gender	4	Was the researcher male or female?	Female
Experience and training	5	What experience or training did the researcher have?	PhD student/r
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	N/A
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic anal
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	N/A
Sample size	12	How many participants were in the study?	639 response
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Online
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Online health forums (51/639 specified their gender in posts).
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	N/A
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	N/A
Data saturation	22	Was data saturation discussed?	Yes
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	1 (2 spot chec
Description of the coding tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	Derived from t
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

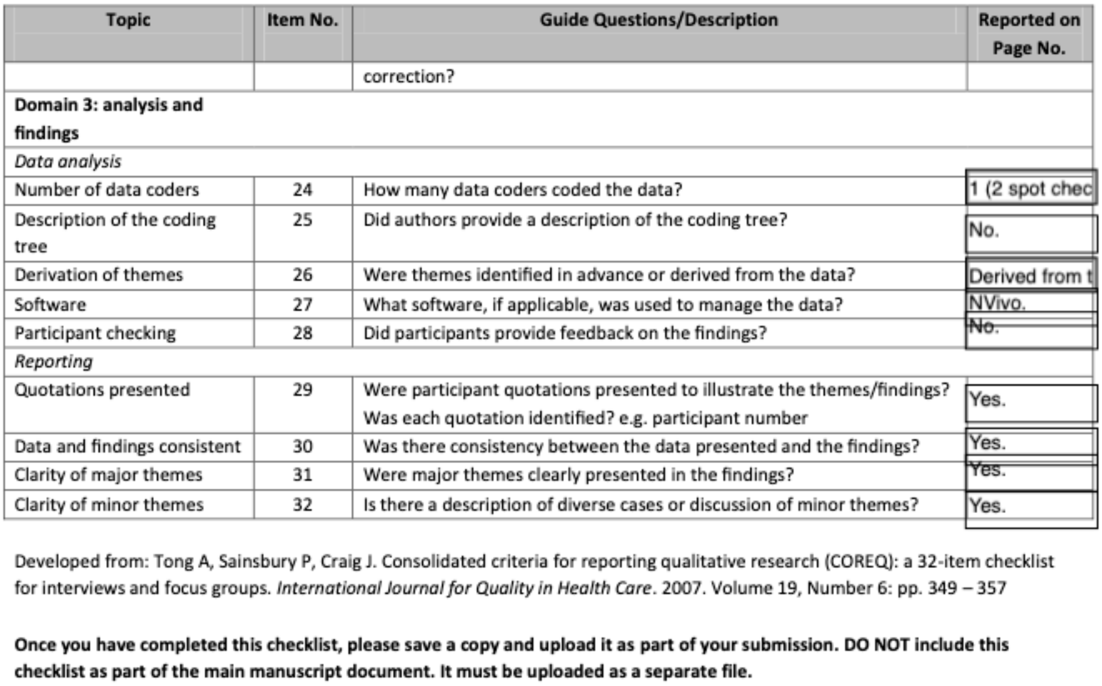
Appendix 11: The Consolidated Criteria for Reporting Qualitative Research (COREQ) (interview study)



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	N/A
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	PhD student
Occupation	3	What was their occupation at the time of the study?	PhD student/r
Gender	4	Was the researcher male or female?	Female
Experience and training	5	What experience or training did the researcher have?	PhD student/r
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No.
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Occupation (PhD research)
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Occupation (PhD research)
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic anal
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Convenience
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	Email
Sample size	12	How many participants were in the study?	31 participants
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Online interviews
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No.
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Public and HCP participants
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes.
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Audio.
Field notes	20	Were field notes made during and/or after the inter view or focus group?	After the interview.
Duration	21	What was the duration of the inter views or focus group?	40-60 minutes.
Data saturation	22	Was data saturation discussed?	Yes.
Transcripts returned	23	Were transcripts returned to participants for comment and/or	No.



Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	1 (2 spot chec
Description of the coding tree	25	Did authors provide a description of the coding tree?	No.
Derivation of themes	26	Were themes identified in advance or derived from the data?	Derived from t
Software	27	What software, if applicable, was used to manage the data?	NVivo.
Participant checking	28	Did participants provide feedback on the findings?	No.
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes.
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes.
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes.
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes.

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

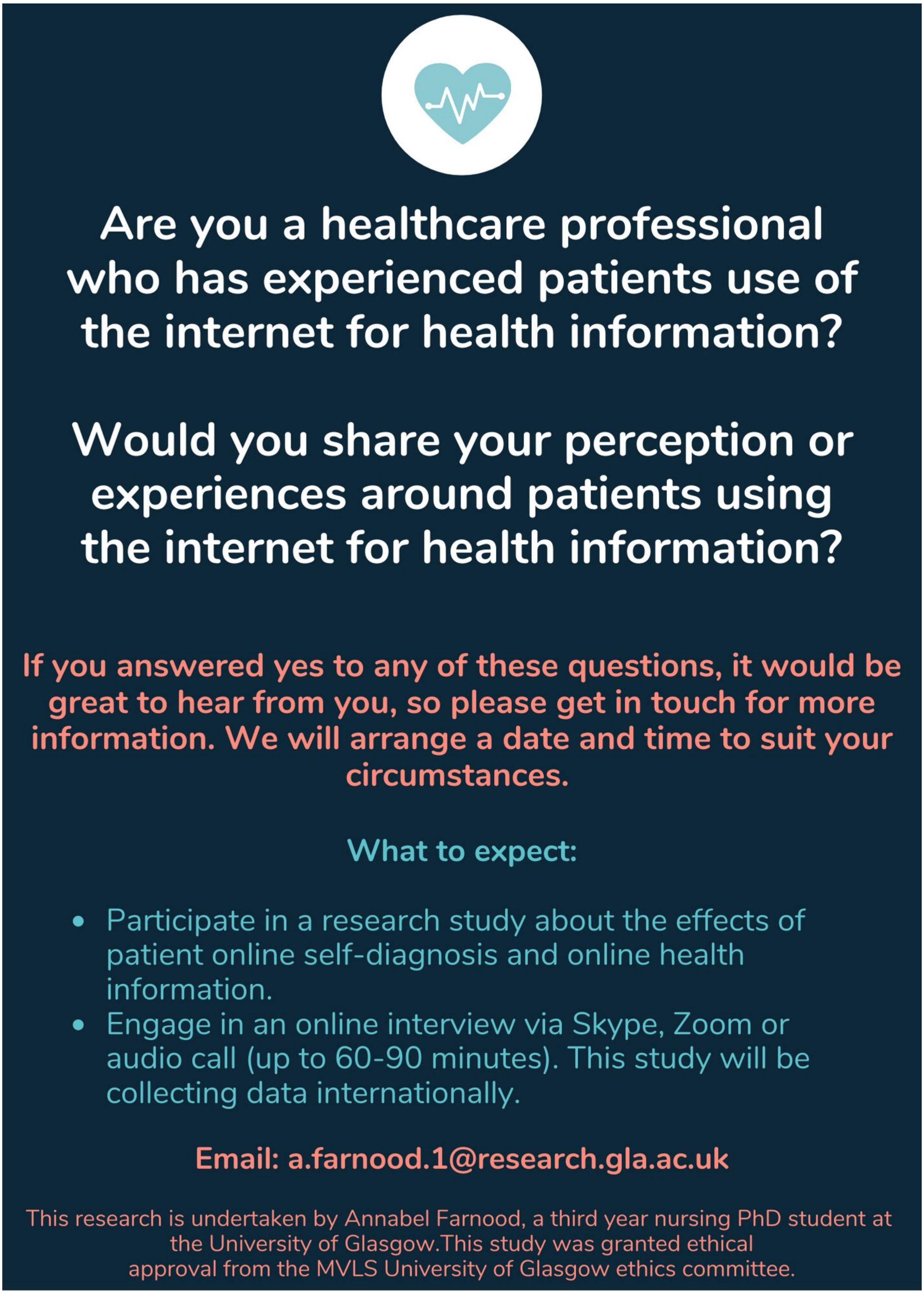
Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 12: HCP recruitment flyer

Have you worked with internet-informed patients?

Are you a healthcare professional that could help with a PhD research project?

Annabel Farnood
PhD Student (Nursing)
The University of Glasgow



Are you a healthcare professional who has experienced patients use of the internet for health information?

Would you share your perception or experiences around patients using the internet for health information?

If you answered yes to any of these questions, it would be great to hear from you, so please get in touch for more information. We will arrange a date and time to suit your circumstances.

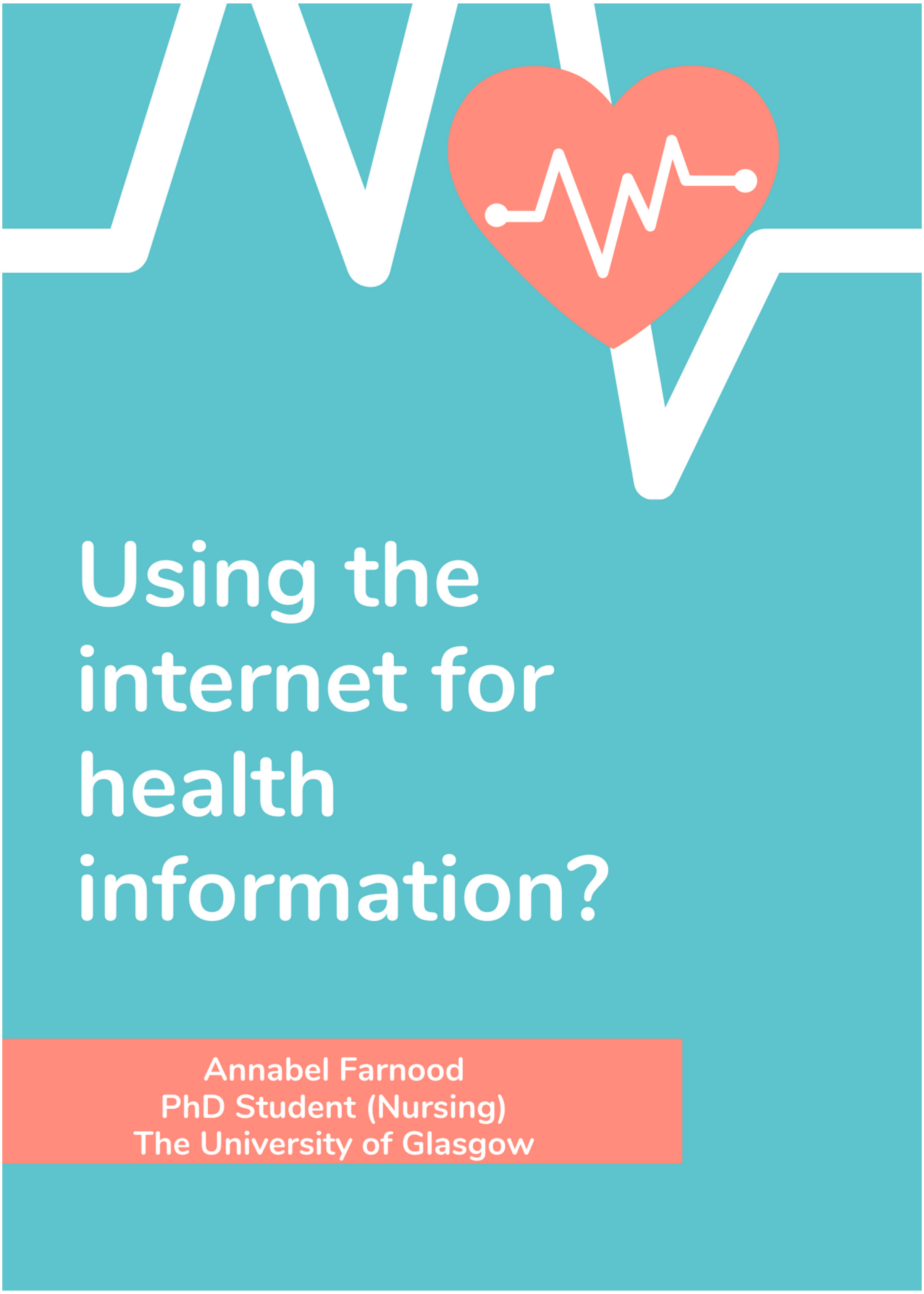
What to expect:

- Participate in a research study about the effects of patient online self-diagnosis and online health information.
- Engage in an online interview via Skype, Zoom or audio call (up to 60-90 minutes). This study will be collecting data internationally.

Email: a.farnood.1@research.gla.ac.uk

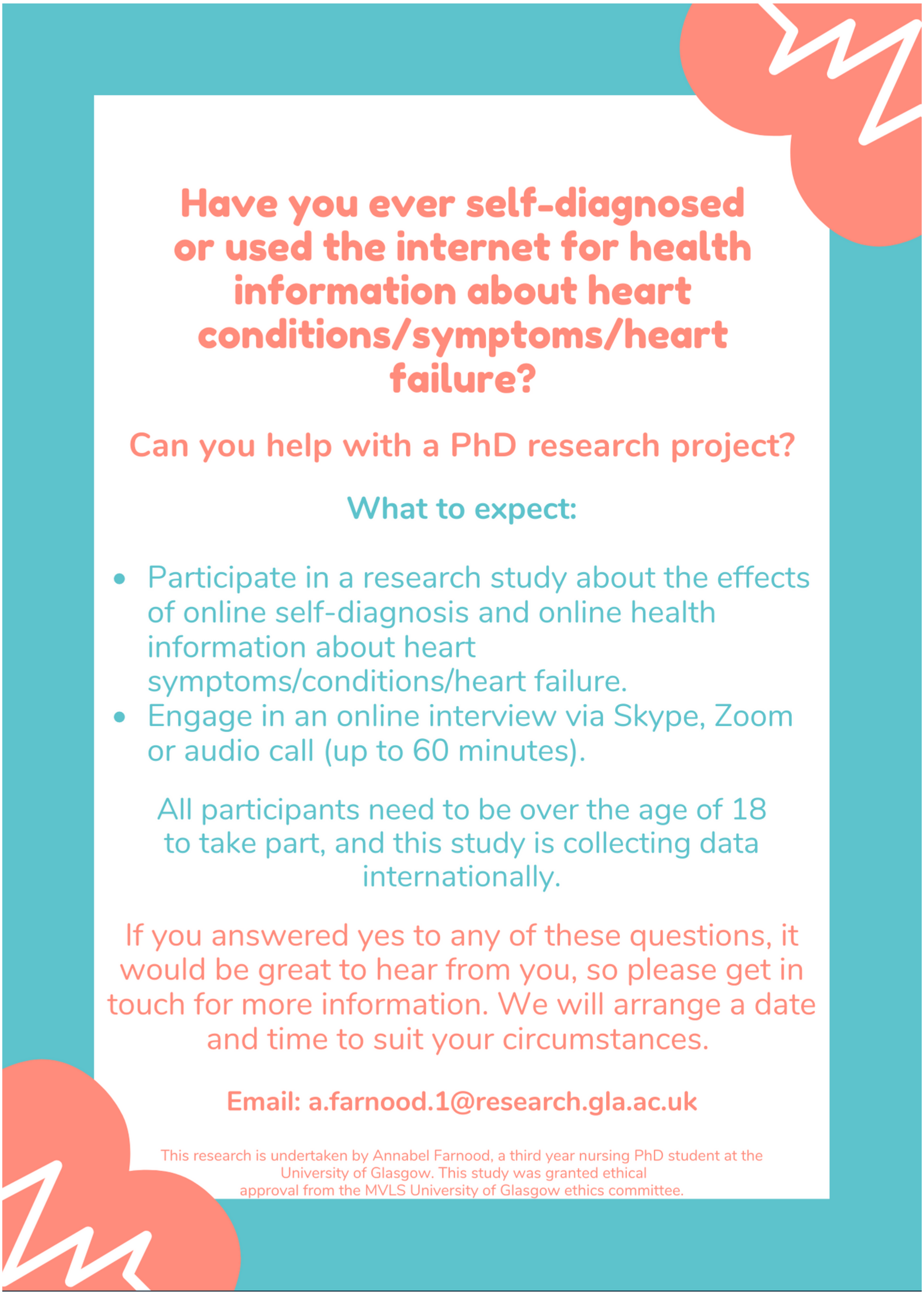
This research is undertaken by Annabel Farnood, a third year nursing PhD student at the University of Glasgow.This study was granted ethical approval from the MVLS University of Glasgow ethics committee.

Appendix 13: Public recruitment flyer



Using the internet for health information?

Annabel Farnood
PhD Student (Nursing)
The University of Glasgow



Have you ever self-diagnosed or used the internet for health information about heart conditions/symptoms/heart failure?

Can you help with a PhD research project?

What to expect:

- Participate in a research study about the effects of online self-diagnosis and online health information about heart symptoms/conditions/heart failure.
- Engage in an online interview via Skype, Zoom or audio call (up to 60 minutes).

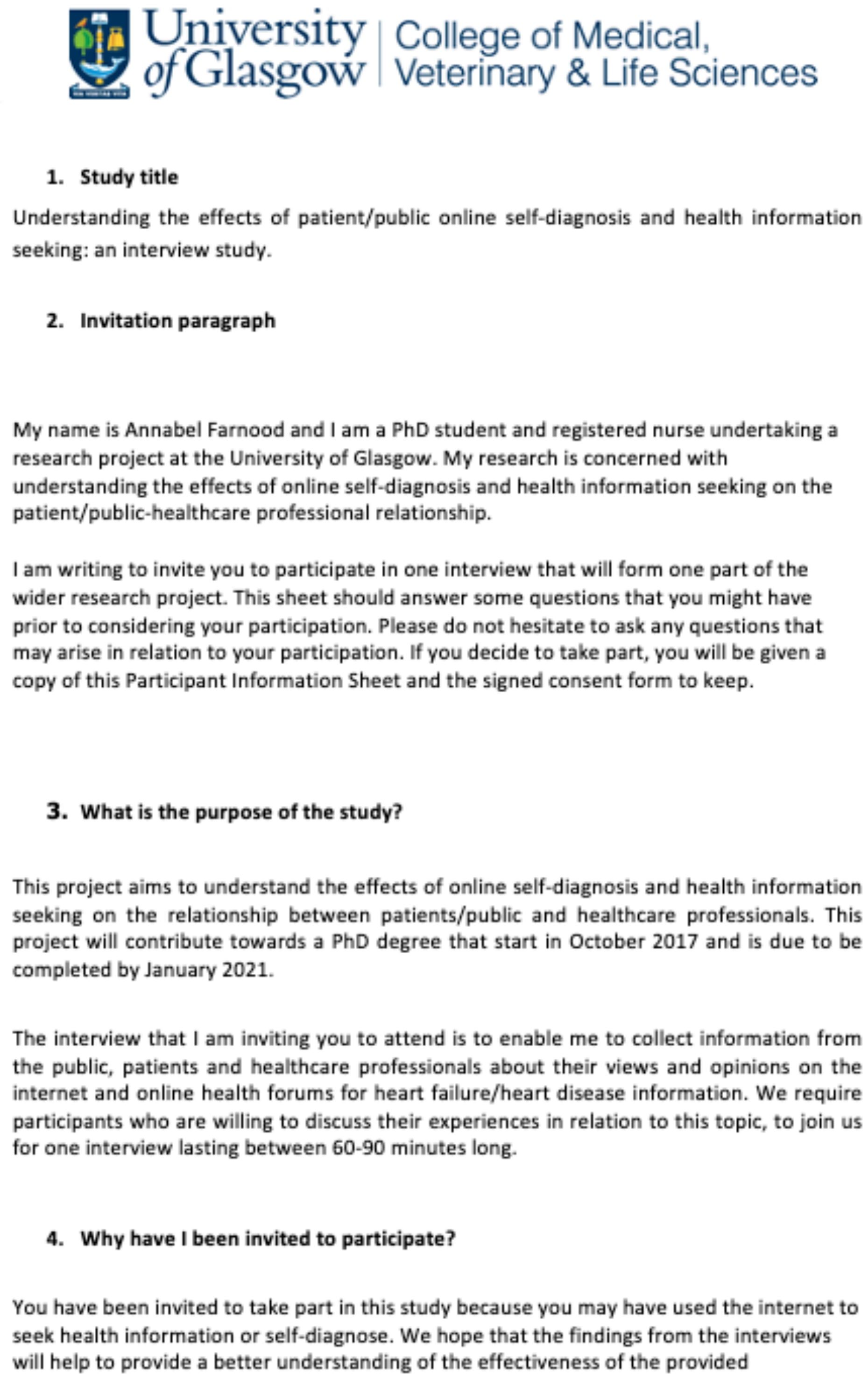
All participants need to be over the age of 18 to take part, and this study is collecting data internationally.

If you answered yes to any of these questions, it would be great to hear from you, so please get in touch for more information. We will arrange a date and time to suit your circumstances.

Email: a.farnood.1@research.gla.ac.uk

This research is undertaken by Annabel Farnood, a third year nursing PhD student at the University of Glasgow. This study was granted ethical approval from the MVLS University of Glasgow ethics committee.

Appendix 14: Participant information sheet



University of Glasgow | College of Medical, Veterinary & Life Sciences

1. Study title

Understanding the effects of patient/public online self-diagnosis and health information seeking: an interview study.

2. Invitation paragraph

My name is Annabel Farnood and I am a PhD student and registered nurse undertaking a research project at the University of Glasgow. My research is concerned with understanding the effects of online self-diagnosis and health information seeking on the patient/public-healthcare professional relationship.

I am writing to invite you to participate in one interview that will form one part of the wider research project. This sheet should answer some questions that you might have prior to considering your participation. Please do not hesitate to ask any questions that may arise in relation to your participation. If you decide to take part, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

3. What is the purpose of the study?

This project aims to understand the effects of online self-diagnosis and health information seeking on the relationship between patients/public and healthcare professionals. This project will contribute towards a PhD degree that start in October 2017 and is due to be completed by January 2021.

The interview that I am inviting you to attend is to enable me to collect information from the public, patients and healthcare professionals about their views and opinions on the internet and online health forums for heart failure/heart disease information. We require participants who are willing to discuss their experiences in relation to this topic, to join us for one interview lasting between 60-90 minutes long.

4. Why have I been invited to participate?

You have been invited to take part in this study because you may have used the internet to seek health information or self-diagnose. We hope that the findings from the interviews will help to provide a better understanding of the effectiveness of the provided information online, and the impact this has on the patient/public-healthcare professional relationship.

All study participants must be over the age of 18 and participants can only be involved if at least one of the following criteria is matched:

- You have looked up information online about heart failure or heart disease.
- You have self-diagnosed heart failure or heart disease.
- You are a member of the public.
- You are nurse or doctor working and had experience with people using the online health information for heart failure or heart disease.

5. Do I have to take part?

No, there is no mandatory requirement for participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. The data we have collected until that point, can be kept with full confidentiality.

6. What will happen to me if I take part?

- You will be required to attend one online interview.
- Interviews will be one on one and online/phone call.
- One on one interviews will be up to 60-90 minutes.
- Demographic data will be collected: age, sex, location and occupation.
- The interview will be an opportunity for you to share your thoughts, feelings and ideas related to your experiences on this topic.
- There are no right or wrong answers.
- You will not need to prepare anything. Participating and engaging in the discussions is all that is required.
- The discussions will be voice recorded; however, the results will be anonymised as confidentiality is a vital element of the interviews.

7. What do I have to do?

If you are interested in participation in this study, please contact Annabel Farnood by phone or email.

You can withdraw from participation at any point in the study. If you decide to participate, you will be required to attend the interview on the agreed date and time.

8. What are the possible disadvantages and risks of taking part?

We understand that your time is very valuable, and we acknowledge that participating may reduce your free time. Discussion about any health conditions can be quite emotional. I will be available to chat after the interviews if you would like to reflect or ask questions privately. There is no potential risk to taking part as the discussions will be anonymised and your input will not be identifiable.

9. What are the possible benefits of taking part?

There is no financial incentive for participating but your input will be extremely valuable for the development of this research project. The findings from the interview will also be published in a professional journal and may help to inform other research projects. There are no direct personal benefits to taking part in this study. After the interview participations, I would be happy to update you with the progress of this study so you can be kept informed about the overall findings, if you wish.

10. Will my taking part in this study be kept confidential?

All information that is collected about you, or responses that you provide, during the interviews, will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and contact details removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password–protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

11. What will happen to my data?

- The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

- Researchers from the University of Glasgow collect, store and process all personal information in accordance with the General Data Protection Regulation (May 2018).

- Your data will form part of the study result that may be published in expert journals, presentations, student thesis for other researchers to use. There will be no identifiable information included in any of these publications.

12. What will happen to the results of the research study?

The overall results of the study will form one part of a wider research study that will primarily be included in Annabel Farnood's university thesis. The results will also be included in a publication for an expert research journal. We may directly quote you in these reports however, no information or details will be identifiable and will be kept anonymous.

13. Who is organising and funding the research?

I am the project leader and I have support and guidance from two supervisors. Professor Bridget Johnston is a Florence Nightingale Foundation Chair in Clinical Nursing Practice Research at the University of Glasgow, and also holds a clinical role within NHS Greater Glasgow and Clyde. Professor Frances Mair is a Norie Miller Professor of Primary Care Research (General Practice & Primary Care) within the School of Medicine, Dentistry & Nursing at the University of Glasgow.

14. Who has reviewed the study?

This project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

15. Contact for Further Information

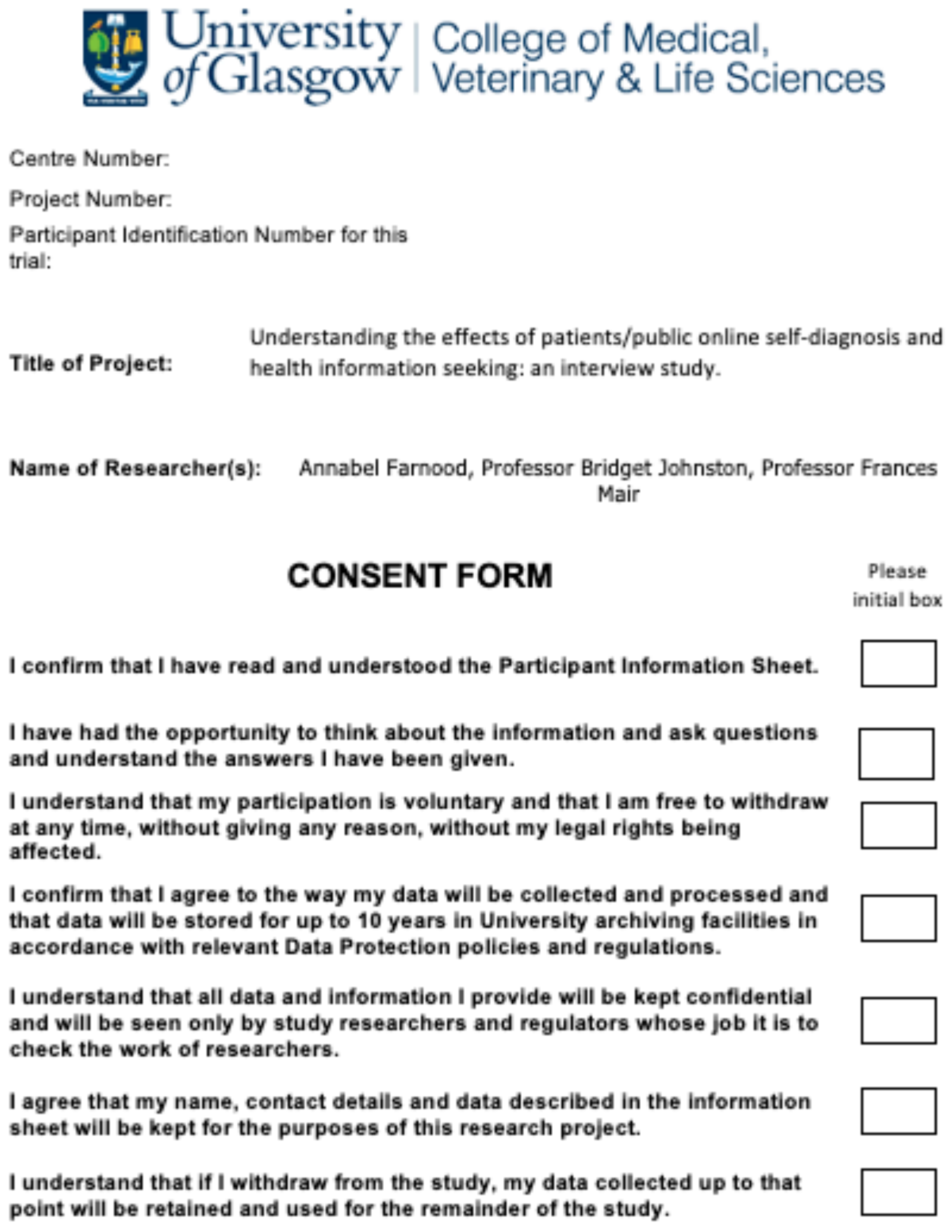
Annabel Farnood
Email: a.farnood.1@research.gla.ac.uk
Direct line: 01413303754

Supervisors:

Professor Bridget Johnston
Email: bridget.johnston@glasgow.ac.uk

Professor Frances Mair
Email: frances.mair@glasgow.ac.uk

Appendix 15: Consent form



University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number:

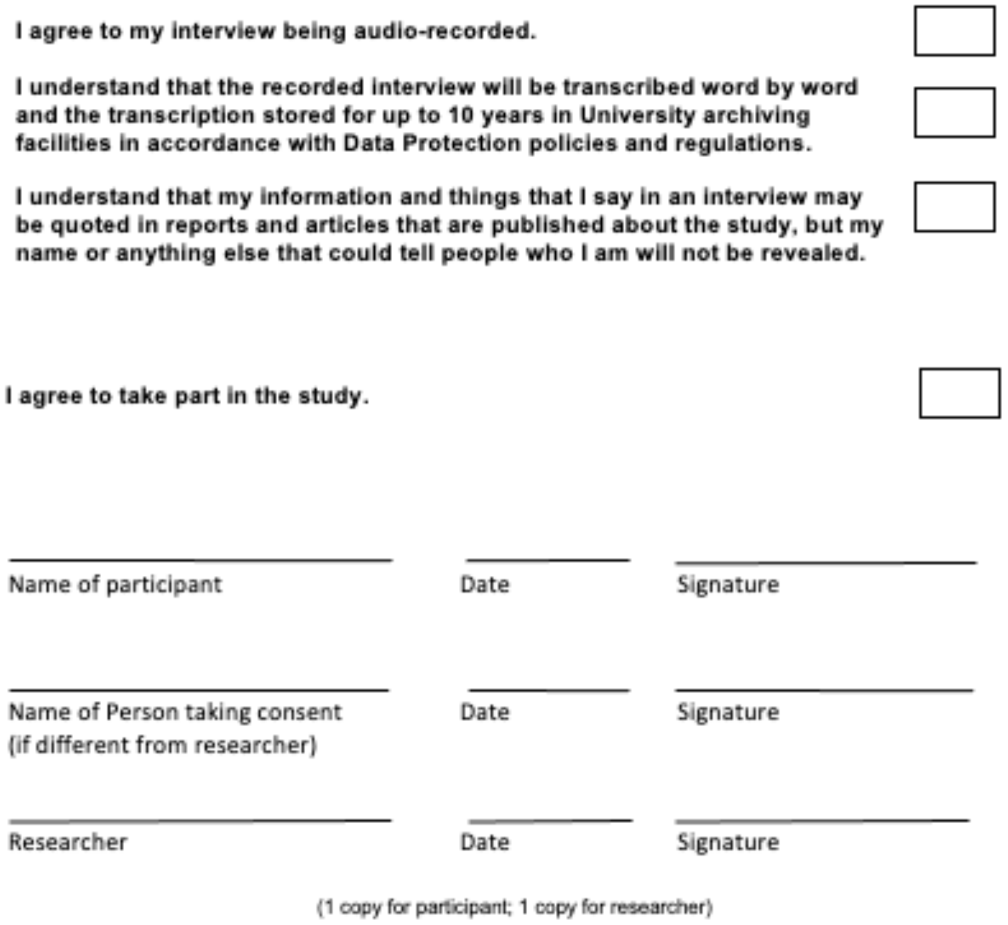
Participant Identification Number for this trial:

Title of Project: Understanding the effects of patients/public online self-diagnosis and health information seeking: an interview study.

Name of Researcher(s): Annabel Farnood, Professor Bridget Johnston, Professor Frances Mair

CONSENT FORM

	Please initial box
I confirm that I have read and understood the Participant Information Sheet.	☐
I have had the opportunity to think about the information and ask questions and understand the answers I have been given.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.	☐
I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.	☐
I agree that my name, contact details and data described in the information sheet will be kept for the purposes of this research project.	☐
I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.	☐



I agree to my interview being audio-recorded. ☐

I understand that the recorded interview will be transcribed word by word and the transcription stored for up to 10 years in University archiving facilities in accordance with Data Protection policies and regulations. ☐

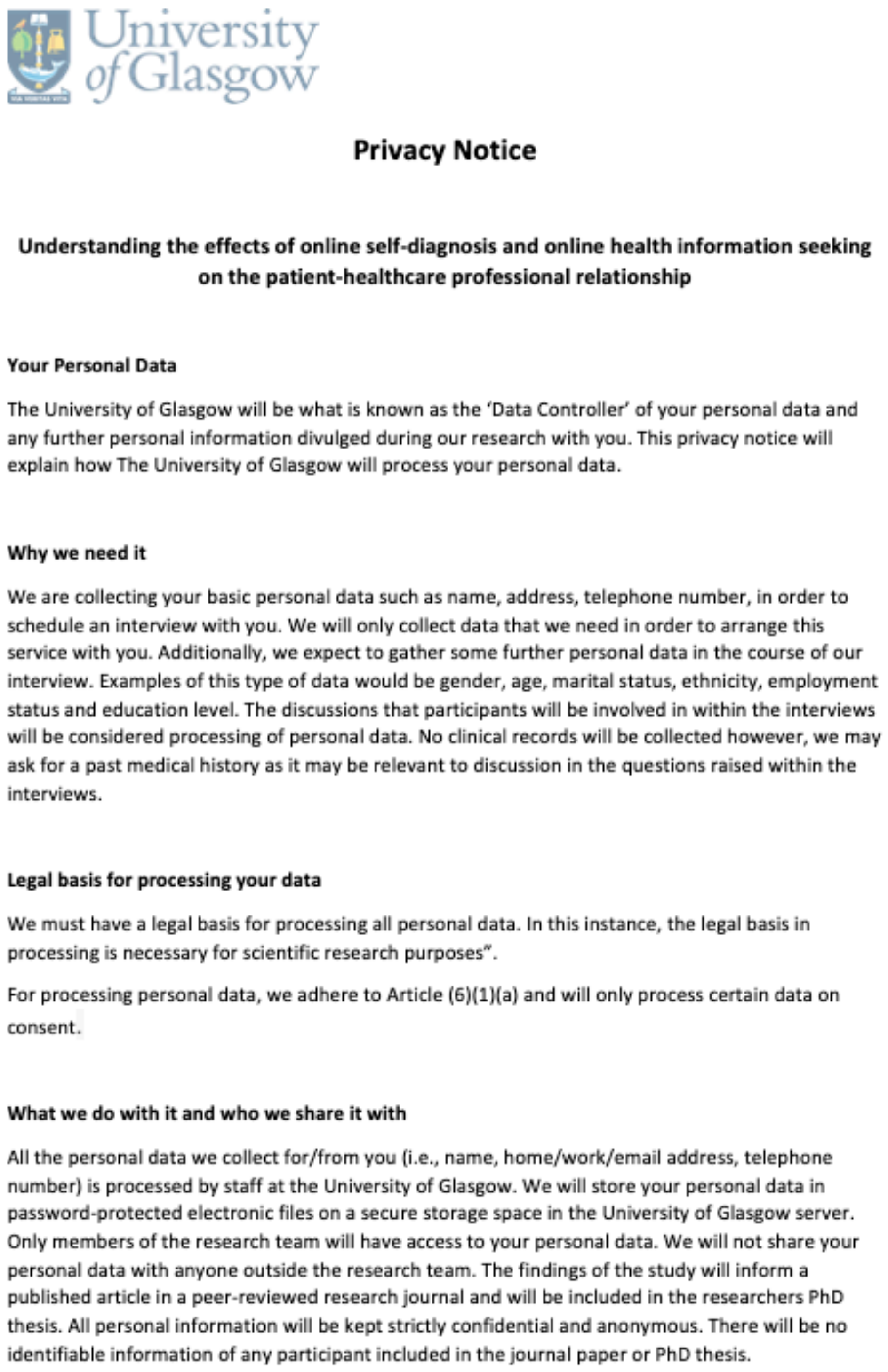
I understand that my information and things that I say in an interview may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

I agree to take part in the study. ☐

Name of participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

(1 copy for participant; 1 copy for researcher)

Appendix 16: Privacy notice



University of Glasgow

Privacy Notice

Understanding the effects of online self-diagnosis and online health information seeking on the patient-healthcare professional relationship

Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data and any further personal information divulged during our research with you. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it

We are collecting your basic personal data such as name, address, telephone number, in order to schedule an interview with you. We will only collect data that we need in order to arrange this service with you. Additionally, we expect to gather some further personal data in the course of our interview. Examples of this type of data would be gender, age, marital status, ethnicity, employment status and education level. The discussions that participants will be involved in within the interviews will be considered processing of personal data. No clinical records will be collected however, we may ask for a past medical history as it may be relevant to discussion in the questions raised within the interviews.

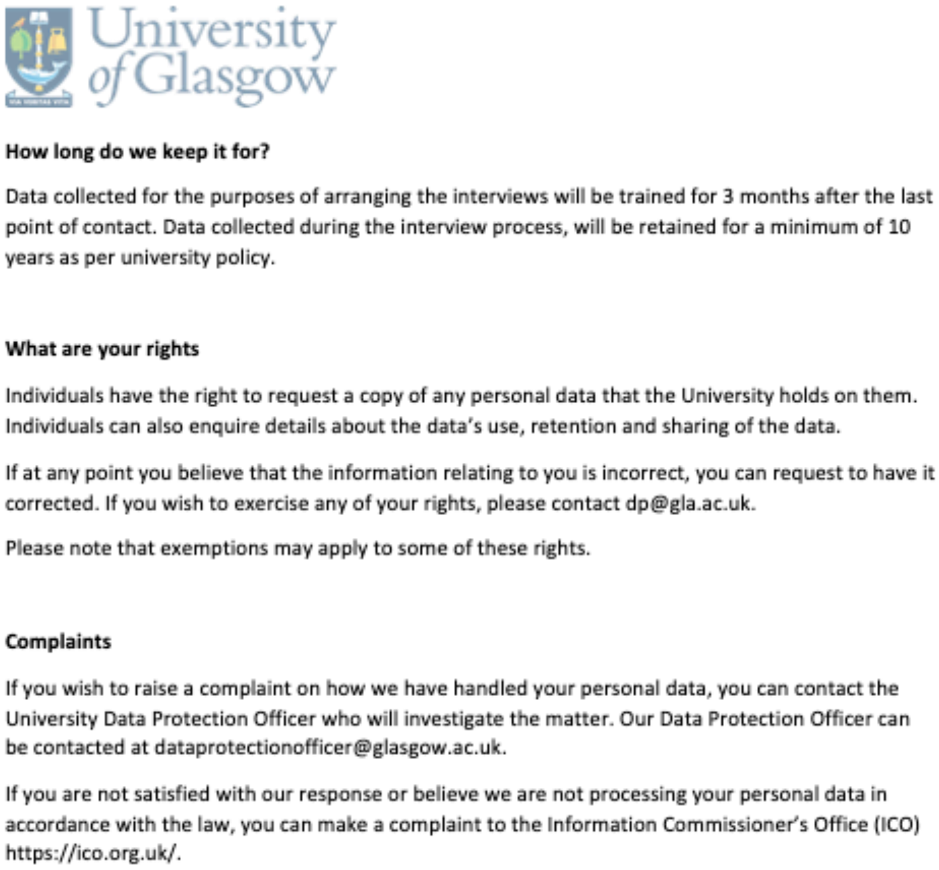
Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis in processing is necessary for scientific research purposes".

For processing personal data, we adhere to Article (6)(1)(a) and will only process certain data on consent.

What we do with it and who we share it with

All the personal data we collect for/from you (i.e., name, home/work/email address, telephone number) is processed by staff at the University of Glasgow. We will store your personal data in password-protected electronic files on a secure storage space in the University of Glasgow server. Only members of the research team will have access to your personal data. We will not share your personal data with anyone outside the research team. The findings of the study will inform a published article in a peer-reviewed research journal and will be included in the researchers PhD thesis. All personal information will be kept strictly confidential and anonymous. There will be no identifiable information of any participant included in the journal paper or PhD thesis.



How long do we keep it for?

Data collected for the purposes of arranging the interviews will be trained for 3 months after the last point of contact. Data collected during the interview process, will be retained for a minimum of 10 years as per university policy.

What are your rights

Individuals have the right to request a copy of any personal data that the University holds on them. Individuals can also enquire details about the data's use, retention and sharing of the data.

If at any point you believe that the information relating to you is incorrect, you can request to have it corrected. If you wish to exercise any of your rights, please contact dp@gla.ac.uk.

Please note that exemptions may apply to some of these rights.

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter. Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk.

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can make a complaint to the Information Commissioner's Office (ICO) https://ico.org.uk/.

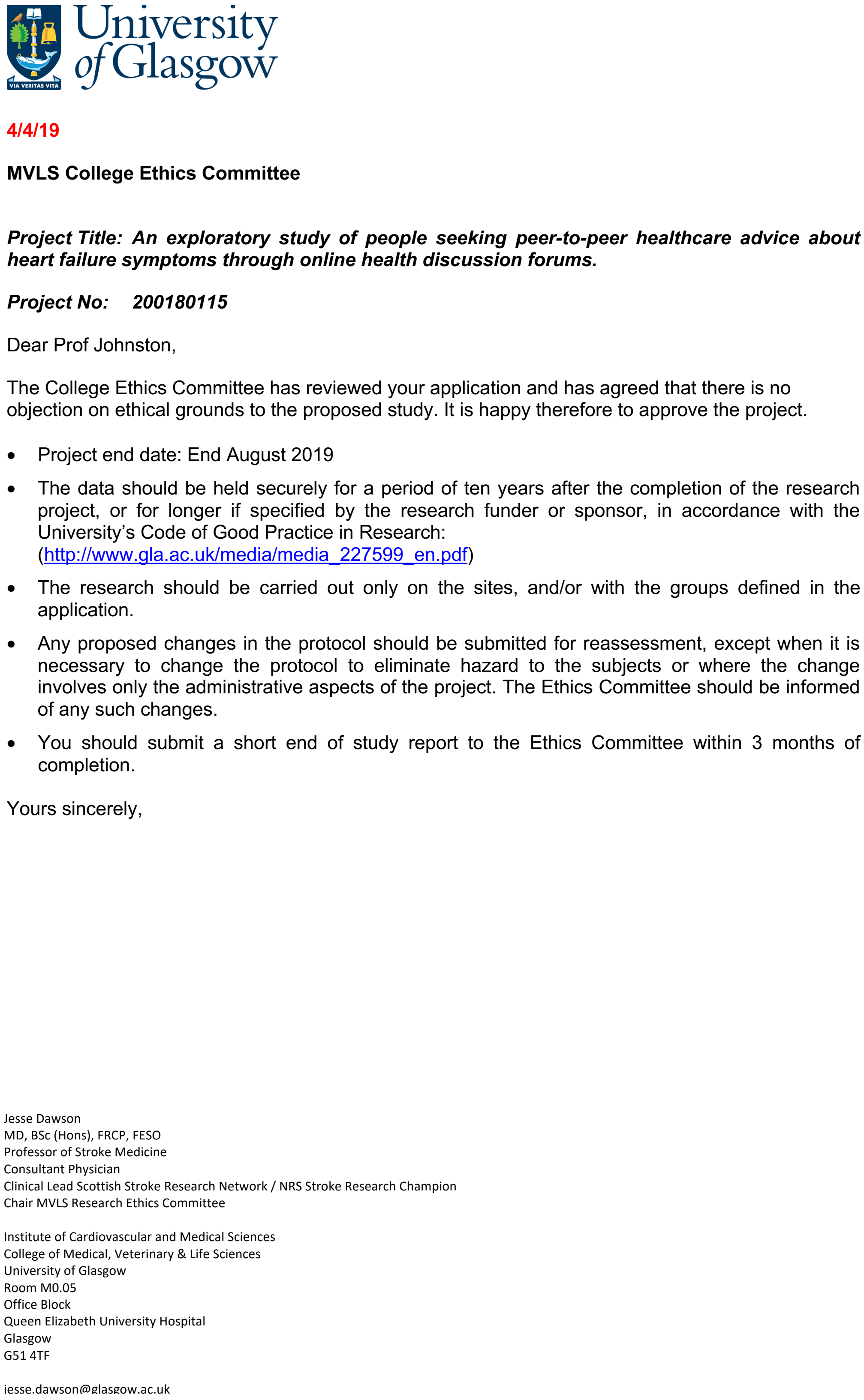
Appendix 17: Interview schedule - members of the public

Questions	Probes
1. If we could begin by just explaining your experiences with self-diagnosis and internet health information? (That led you to this study – relatability).	- Positives and negatives? (adv/disadv).
2. What was your motivation for using the internet? •	- How did you feel before you made the search? - Did you search on a search engine or go straight to a specific website to find the answers? - What sources did/do you use?
3. When you found the information online, what did you do with it?	- How did it make you feel? - What was your next step?
4. The relationship with healthcare professionals.	- Do you present your internet findings to your HCP? - Do you prepare for your appointments?
5. Peer-to-peer healthcare.	- Are you familiar with online health forums or social media support groups? - If so, do you use them? What are your thoughts/experiences on them? - If not, why not?
6. To summarise, what are your overall perceptions of the use of the internet for self-diagnosis and health information (for heart failure/symptoms/conditions related) AND how would you say this has impacted your relationship with your HCP(s)?	- Are you satisfied or dis-satisfied etc?

Appendix 18: Interview schedule - healthcare professionals

Questions	Probes
1. What are your experiences of patients use of the internet for self-diagnosis and health information seeking?	- What led you to this study? - General perceptions?
2. In the consultation.	- What have been your experiences with internet-informed patients in the consultation? - Have you experienced internet-informed patients in appointments having self-diagnosed heart failure/presented with internet research? - How does it make you feel when patient's bring online health findings? - How do you communicate with internet-informed patients (approaches)? - Do you provide patients with online resources? - Do you feel internet health impacts your relationship with patients?
3. How do you feel about peer-to-peer healthcare? My notes: Online health forums/social media support groups	- Are you familiar with these sources? - What are your views on these types of sources? - Would you recommend them to patients?
4. To summarise, what are your overall perceptions of patients use of the internet for self-diagnosis and health information (general and heart failure/symptoms/conditions related) AND how would you say this has impacted your relationship with your patients?	Satisfied or dissatisfied?

Appendix 19: Ethics approval letter for online health forum studies



4/4/19

MVLS College Ethics Committee

Project Title: An exploratory study of people seeking peer-to-peer healthcare advice about heart failure symptoms through online health discussion forums.

Project No: 200180115

Dear Prof Johnston,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End August 2019
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
College of Medical, Veterinary & Life Sciences
University of Glasgow
Room M0.05
Office Block
Queen Elizabeth University Hospital
Glasgow
G51 4TF

jesse.dawson@glasgow.ac.uk

Appendix 20: Ethics approval letter for interview study

20th March 2020

MVLS College Ethics Committee

Understanding the effects of patient/public online self-diagnosis and health information seeking: a focus group/interview study

Project No: 200190100

Dear Prof Johnston,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: As stated in application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

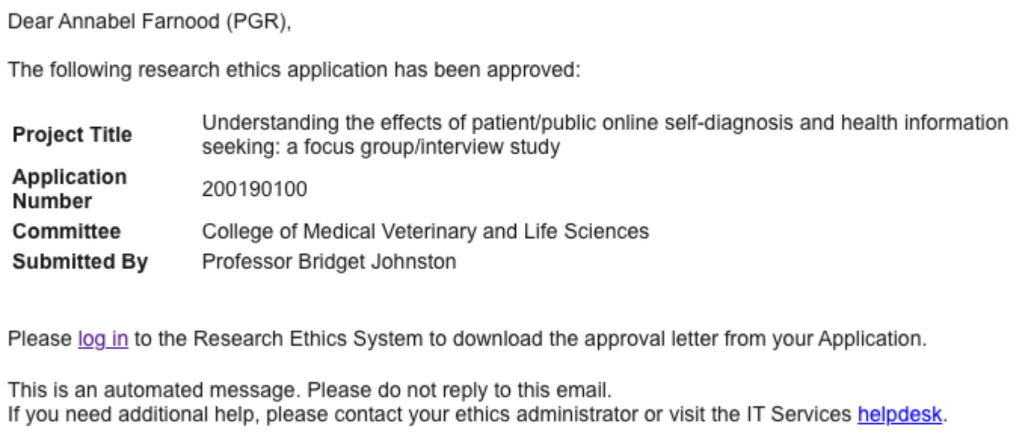
Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
College of Medical, Veterinary & Life Sciences
University of Glasgow
Room M0.05
Office Block
Queen Elizabeth University Hospital
Glasgow
G51 4TF

jesse.dawson@glasgow.ac.uk

Appendix 21: Ethics approval to begin interview study following COVID-19 delay



Dear Annabel Farnood (PGR),

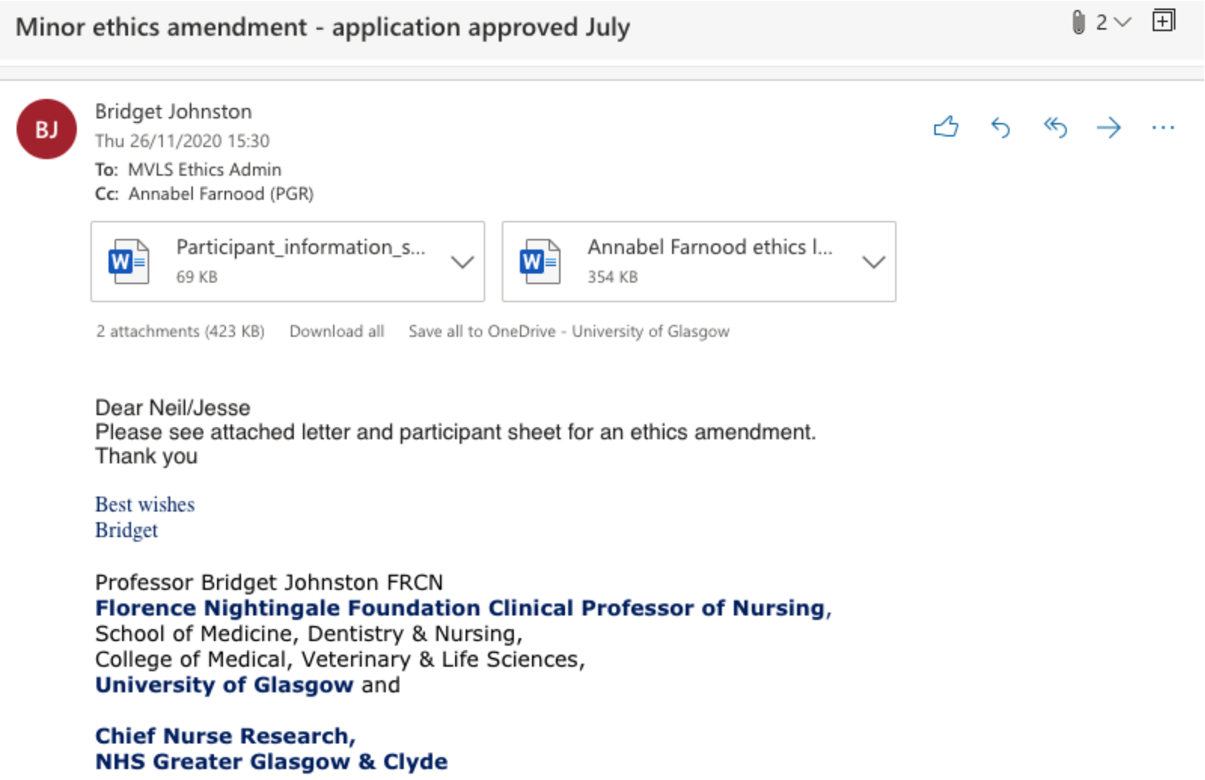
The following research ethics application has been approved:

Project Title	Understanding the effects of patient/public online self-diagnosis and health information seeking: a focus group/interview study
Application Number	200190100
Committee	College of Medical Veterinary and Life Sciences
Submitted By	Professor Bridget Johnston

Please log in to the Research Ethics System to download the approval letter from your Application.

This is an automated message. Please do not reply to this email.
If you need additional help, please contact your ethics administrator or visit the IT Services helpdesk.

Appendix 22: Ethics amendment for interview study



Minor ethics amendment - application approved July

BJ

Bridget Johnston
Thu 26/11/2020 15:30
To: MVLS Ethics Admin
Cc: Annabel Farnood (PGR)

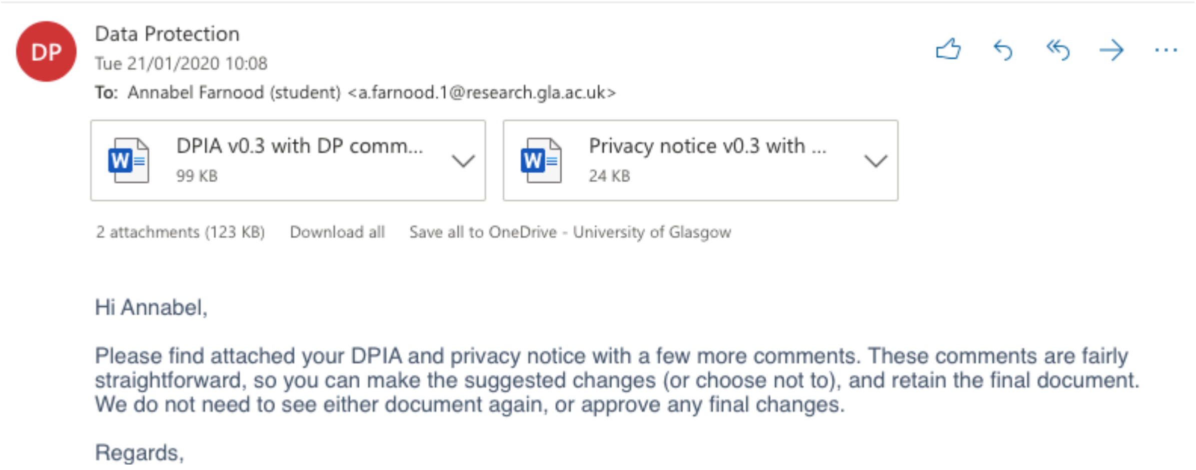
Dear Neil/Jesse
Please see attached letter and participant sheet for an ethics amendment.
Thank you

Best wishes
Bridget

Professor Bridget Johnston FRCN
Florence Nightingale Foundation Clinical Professor of Nursing,
School of Medicine, Dentistry & Nursing,
College of Medical, Veterinary & Life Sciences,
University of Glasgow and

Chief Nurse Research,
NHS Greater Glasgow & Clyde

Appendix 23: Data protection impact assessment approval



Data Protection
Tue 21/01/2020 10:08
To: Annabel Farnood (student) <a.farnood.1@research.gla.ac.uk>

Hi Annabel,

Please find attached your DPIA and privacy notice with a few more comments. These comments are fairly straightforward, so you can make the suggested changes (or choose not to), and retain the final document. We do not need to see either document again, or approve any final changes.

Regards,

Appendix 24: Publication in BMC Medical Informatics and Decision Making (Chapter Five - Mixed Methods Systematic Review)

Farnood *et al. BMC Medical Informatics and Decision Making* (2020) 20:253
https://doi.org/10.1186/s12911-020-01243-6

BMC Medical Informatics and
Decision Making

REVIEW **Open Access**

A mixed methods systematic review of the effects of patient online self-diagnosing in the 'smart-phone society' on the healthcare professional-patient relationship and medical authority

Annabel Farnood[1*], Bridget Johnston[1,2] and Frances S. Mair[3]

Abstract

Background: As technology continues to advance, the internet is becoming increasingly popular. Self-diagnosis and health information seeking online is growing more common and it will be important to understand the influence this may have on the patient-healthcare professional relationship.

Methods: A mixed-method systematic review of quantitative, qualitative and mixed method studies concerning the public and healthcare professionals' perceptions of online self-diagnosis and health information seeking and how this can impact the patient-healthcare professional relationship. We searched MEDLINE, EMBASE, CINAHL, ACM & SCOPUS between 2007 and 2018. Relevant data were extracted, and a thematic analysis was conducted and conceptualised using the Normalisation Process Theory framework.

Results: Of 6107 records identified, 25 articles met the review eligibility criteria which included 16 qualitative, 8 quantitative and 1 mixed method study. The findings indicated that patients found the internet as a complementary information source alongside healthcare professionals. Health care professionals were perceived to be the most reliable and valued information source. People feel responsible for their own health and find the internet to be a source that provides information rapidly with accessibility at their convenience. Most healthcare professionals agreed on the importance of collaboration with patients and the need to develop a partnership and shared decision-making process but struggled to find time in the consultation to do so efficiently. Some healthcare professionals felt that the internet was advantageous for patients looking after their own health, while others felt it was due to a lack of trust in their expertise. Patients tended to present information to the healthcare professional to support the therapeutic relationship rather than to challenge it and to become more involved in the decision-making process of their healthcare.

(Continued on next page)

---

* Correspondence: a.farnood.1@research.gla.ac.uk
[1]School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences University of Glasgow, Glasgow, Scotland
Full list of author information is available at the end of the article

(Continued from previous page)

Conclusion: The results of this review suggests that patients value healthcare professionals as a source of medical advice more than the internet. While health professionals' views were mixed our findings indicate that online health information seeking can potentially improve the patient-healthcare professional relationship as patients reported they usually conducted an online search to form a partnership with the healthcare professional as opposed to trying to prove them wrong.

Keywords: Online self-diagnosis, online health information, Medical information, Internet, Information seeking, Self-diagnosis, Digital health, Professional-patient relationship

Background

Online health information seeking and self-diagnosis is a growing phenomenon internationally [1]. Due to technology advances, the internet is more accessible than ever, with usage increasing, currently 84% of the US population now use online services [2]. The rising use of smartphones [3] and rapidly increasing availability of health information on the internet has led to more people using the internet as their first healthcare resource, often before seeking professional advice [4]. Consequently, there is growing interest in the effect of these changes in behaviour on health outcomes as well as the potential impact on the healthcare professional (HCP) and patient relationship.

A US survey reported that by 2013, more than one-third of US adults were searching online for medical information for self-diagnosis [5]. While a 2015 UK-wide survey of General Practitioners (GPs) reported that three-quarters of GPs have noticed an increase in people self-diagnosing online and, 21% have experienced people presenting with the information they have found online [6]. The main concern reported by GPs in this survey was that online self-diagnoses would lead to increased appointment-making by the 'worried well'. It has also been suggested that doctors may feel intimidated by online self-diagnosis [7]. Concerns have also been raised from within the nursing profession that some of the information being accessed by people may be of poor quality, and instead of being based on robust clinical evidence, merely represents the commercial interests of the website owners [8].

Previous research on the topic of online self-diagnosis and health information seeking tends to focus on the quality of health information online [9] and the characteristics of online health information seekers [10]. Other research has explored patient satisfaction with HCP communication and patient-HCP interaction [11]. This systematic review investigates whether patient online self-diagnosis and health information seeking is affecting the patient-HCP relationship, and the perceptions of patients and HCPs regarding online self-diagnosis and searching for health information online. The patient-HCP relationship has been known to influence health outcomes and can improve the patient experience in the healthcare system [12, 13], hence efforts to understand whether and how this relationship may be influenced by increased health information seeking online is an important evidence gap.

This paper aims to address the following three research questions:

1. What are the effects of patients seeking online health information on the healthcare professional-patient relationship and medical authority?
2. How do healthcare professionals perceive patients' use of online health information?
3. How do public/patients perceive the use of online health information?

Methods

This mixed method systematic review was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) quality requirements [14]. The protocol is registered on PROSPERO [15], the International Prospective Register of Systematic Reviews (CRD42018084230).

Search strategy

The systematic literature search was conducted using five databases: MEDLINE, EMBASE, CINAHL, ACM and SCOPUS. All searches were conducted using an 'advanced search' functionality, restricted to English language only and published between 2007 and April 2018 (Table 1). Although self-diagnosis has been happening for many years, the smartphone has made this phenomenon increase due to the rapid and accessible health information that is available to consumers online [16]. Therefore, this date range was chosen to bring the results in line with the launch of the first Apple smartphone, 'Apple iPhone' in 2007 [15]. The search strategies were conducted using database specific controlled vocabularies and free text terms. The search terms, among others, included 'information seeking behaviour', 'online self-diagnosis', 'internet', 'professional-patient relations' and 'mobile app'. There is not one universal term to describe internet use for health information. Therefore, it was important to search for both self-diagnosis and information seeking behaviour terms, as they can both indicate different types of internet use. Information

Table 1 Inclusion and exclusion criteria

Study type	• Publication date from 2007 - present • English language only • Studies that report primary data (qualitative and quantitative studies), Studies can use any form of qualitative or quantitative methods.	Interest was in papers ranging from the years of 2007–2018 as the first Apple iPhone was created in 2007. As this is a mixed method systematic review, the inclusion of studies that report primary data and use any form of qualitative or quantitative methods were considered appropriate for eligibility. This is to offer a broader scope in answering the research questions, and a better representation of the range of research that has already been undertaken. Study types that were grey literature/ not published in a peer review journal, dissertations/thesis, secondary data analysis, published abstracts, conference proceedings, commentary articles written to propose opinions and letters, or editorials were excluded from the review.
Participants	• Any individual (adult) over the age of 18. This includes patients, the public and health care professionals.	This study will only be reviewing adults aged 18 and over in order to maintain a generational research focus.
Topic	• Any physical health conditions. • Must be in relation to online self-diagnosing and health information seeking on the internet. • Can include any level of the diagnosis process – diagnosis, processing and treatment options. Can include the perceptions of the public and healthcare professionals on the topic. • Patient's use of online forums to communicate health information with other patients.	There is currently a variety of health conditions being searched for on the internet, so this review aims to explore a range of different medical searches instead of specific conditions. Online forums are a commonly used medical resource, therefore were included for eligibility. Mental health was not eligible as this is a broad area and the focus was only on physical health conditions. Cancer and maternal health were excluded as these are both large specialty areas, therefore we focused on all other physical health conditions.
Setting	• Any 'normal' primary care setting (community, primary care clinics, home, online, education facilities).	Since online self-diagnosing can take place in any setting that has internet access or service areas, all normal type settings are deemed appropriate. The clinical setting was only focused in primary care and otherwise any setting outside the clinical area.

seeking may be someone that is already diagnosed but wants to know more information about a specific condition. Self-diagnosis is seeking either the initial diagnosis, or a different diagnosis. These different search terms can show a variety of information platforms being used. 'Endnote X7' was used to remove duplicate citations before screening [17]. The full MEDLINE search strategy can be found in Appendix 1.

Data screening / study selection process

Data screening was performed using a systematic review software named 'DistillerSR' [18]. Title and abstracts were screened by one researcher (AF). All full papers were screened independently by two reviewers (AF, BJ or FM).

Data extraction

A standardised data extraction form adapted from Johnston et al. [19] was used to collect study characteristics for papers that met the eligibility criteria (see Additional files). If there was any uncertainty over the content and applicability of the data for the review, this was resolved through discussion within the team. The data extraction table is listed as Tables 6–8 in Additional files 1, 2, 3.

Quality assessment of included studies

As this is a mixed method systematic review, a quality appraisal tool was required that could assess a diverse range of articles in a systematic way. The mixed methods appraisal tool (MMAT) [20] was chosen because it is designed specifically for mixed method studies and appraises qualitative, quantitative, mixed methods, and other types of empirical studies [21], which fits the criteria for this review. The tool is split into two sections: screening questions and the explanation phase. The mixed method appraisal tool discourages the use of a scoring system and instead offers a detailed presentation of the ratings to provide a better explanation of the quality of the included studies [21]. A spreadsheet template was used on Microsoft Excel with a 'yes' or 'no' answer system in order to gain a score percentage, followed by an explanation column to justify the quality assessment score.

Two reviewers (AF, BJ) independently assessed the quality of the eligible studies for reliability purposes. Discussions were engaged over any discrepancies, with a record kept of how the decisions were reached. All articles that met the study inclusion criteria were kept even if they were found to be methodologically weak based on the quality assessment, as they still have the potential to provide new and valuable insights in a field where the literature is relatively sparse.

Data analysis/synthesis

The findings of qualitative and quantitative studies were tabulated separately.

The included studies were read, and a thematic analysis was undertaken to establish a list of themes and sub-themes [22]. Coding clinics were held to refine the themes identified. Each item of extracted data was coded independently through thematic analysis by researcher AF, and reviewed by two researchers (BJ, FM). Four themes were identified and were then mapped onto the constructs of the Normalisation Process Theory (NPT) [23] to aid conceptualisation of the data (Tables 2 and 3). Any data that fell outside the framework was noted to ensure there was no "shoe-horning" of themes into the framework. NPT is a useful framework to explain and understand how people integrate new interventions into their everyday routines [24]. It has four constructs: coherence; cognitive participation; collective action; and reflexive monitoring and has been successfully used in other systematic reviews [25, 26] (Table 2).

Results

Data screening / study selection process

Database searches retrieved 7026 papers in total which reduced to 6109 after deduplication. We had three phases of screening - title, abstract and full text. Each included a list of questions to pass each phase. 6109 titles were screened and 708 passed to abstract screening. Papers were removed in title screening if they were not relevant to the subject area, not in a peer reviewed journal and not involving humans. 708 abstracts were screened and 289 were assessed for full text screening. Abstracts were excluded for the same reasons in title screening, but also assessed for the correct setting, if they answered the research questions and if they were about physical health. The final number of papers deemed eligible to be included from the database search, was 23.

Backward and forward chaining was implemented to ensure that no key articles were missed. During this process, another two papers were discovered to meet the eligibility criteria for review, making the final number of included papers in this mixed methods systematic review, 25 (see Fig. 1).

Study characteristics

Of the 25 eligible papers, there were 16 qualitative, 8 quantitative and 1 mixed method study. (see Tables 6–8 in Additional files 1, 2, 3). Five studies had taken place in the United Kingdom [27–31], six from the United States [32–37], two from Canada [38, 39], one from Austria [40], four from Israel [41–44], two from Australia [45, 46], three from Switzerland [47–49], one from Portugal [50] and one from China [51]. The sample sizes ranged from 11 to 975 with participants including patients either posting online or attending primary care clinics, carers, physicians such as GP's, nurses and various other HCP's. Participants were from a variety of ages, genders, socio-economic groups and ethnicities. Although studies more frequently included middle-aged females and those of 'white' ethnicity. Full detail of study characteristics is provided in the data extraction tables (Tables 6–8 in Additional files 1, 2, 3) and further details of participant characteristics are provided (Table 9 in Additional file 4). Fewer studies explored the HCP's perspectives compared to the patient's perspectives.

Table 2 Normalization Process Theory Core Constructs

Coherence (CO) (Sense-making work)	**Cognitive Participation (CP) (Relationship work)**	**Collective Action (CA) (Enacting work)**	**Reflexive Monitoring (RM) (Appraisal work)**
The sense-making work that people do individually and collectively when they are faced with online self-diagnosis and seeking online health information	The relational work that people do individually and collectively to build and sustain online health information seeking	The operational work that people do by investing effort and time to engage in online self-diagnosis and seeking online health information and to use this information in consultations	The appraisal work that people do when online self-diagnosing or seeking online health information that affects them and others around them
Differentiation:	Initiation	Interactional workability	Systemization
How a set of practices are different from each other	*Key participants driving a set of practices forward*	*Interactional work people do with each other in consultations and other everyday settings*	*Collecting information to determine how effective and useful it is*
Communal specification:	Enrolment	Relational integration	Communal appraisal
A shared understanding of aims and benefits of a set of practices	*Strategies used to engage in tasks and help secure implementation*	*Communicating reliable knowledge about tasks to build accountability and maintain confidence*	*Working together to determine and evaluate the worth of a set of practices*
Individual specification:	Legitimation	Skill set workability	Individual appraisal
An understanding of the responsibilities around a task and practices	*The belief that the set of practices is correct and if it is right to be involved*	*Task allocation and performances*	*Working as individuals to appraise the effects on themselves*
Internalization:	Activation	Contextual Integration	Reconfiguration
Understanding the benefits and values of a set of practices	*Defining actions, behaviours and procedures needed to sustain a practice and stay involved*	*Managing a set of practices through the allocation of different kinds of resources*	*Redefining procedures or modifying practices.*

Table 3 Normalization Process Theory Coding frame for the effects of online self-diagnosis on the patient-healthcare professional relationship

Coherence (Sense-Making Work)	Cognitive Participation (Relationship Work)	Collective Action (Enacting Work)	Reflexive Monitoring (Appraisal Work)
Differentiation	**Initiation**	**Interactional workability**	**Systemization**
Understanding the differences between peoples' use of the internet for online self-diagnosis with the healthcare professional's diagnosis.	HCPs communicating and recommending online health websites to people.	Bringing online health information to consultations and the effect on the consultation and communication between the patient and HCP.	Determining the benefits and risks of online self-diagnosis.
Communal specification	**Enrolment**	**Relational integration**	**Communal appraisal**
Using online health forums and communities to gain information and self-diagnose.	HCPs reactions and behaviours towards internet-informed patients.	The influence (e.g. on confidence) of bringing online information to the relationship between the HCP and internet-informed patients.	Sharing online health information with HCPs and how HCPs react to this.
Individual specification	**Legitimation**	**Skillset workability**	**Individual appraisal**
People achieving an understanding of health information gained through the internet.	HCPs perspectives of online self-diagnosis and if they believe this is beneficial or the right thing for people to do.	The effect of using online information on roles and responsibilities of members of the public or HCPs.	Judging the quality of online information; to what extent do the public or HCPs think the information on the internet is reliable and accurate?
Internalization	**Activation**	**Contextual integration**	**Reconfiguration**
Peoples understanding and perceptions of using the internet to self-diagnose and knowing if this is their preference or if they value the role of the HCP consultations instead.	Communicating effectively with internet-informed people and adapting behaviour towards them.	Integrating online self-diagnosis into social circumstances.	Understanding how online self-diagnosis affects the patient-HCP relationship and altering behaviour and reactions to ensure it is a positive change.

Quality assessment

The quality of reporting in the included studies varied and was measured using the mixed methods approach tool (MMAT). All 25 studies presented clear research questions and collected data to address the questions. Most of the qualitative studies used appropriate data collection methods to answer the research questions, reported the findings adequately derived from the data and provided coherence between qualitative data sources, collection, analysis and interpretation. Most quantitative studies used appropriate statistical analysis to answer the research questions and used appropriate measurements. Almost all the quantitative studies had pre-tested and piloted surveys before use. Fewer studies had samples that accurately represented the target population. Overall, the studies were of moderate quality. See the additional files for full quality assessment table.

Data analysis/synthesis

Four major themes and several subthemes were identified from the synthesis of the literature. The four main themes are: 1) patient perspectives on using the internet to seek health information; 2) healthcare professionals' perspectives on and reactions to internet-informed patients; 3) sharing online health information with healthcare professionals; 4) impact of online medical searches and diagnosis on patient-healthcare professional relationships (Table 4). Participant quotes are provided in the text to corroborate the data in each theme and are summarised in Table 5.

Patient perspectives on using the internet to seek health information

People's opinions of using the internet for self-diagnosis differ, leading to diverse views. Twelve qualitative studies [30, 31, 34, 37–39, 45–47, 49–51] and one mixed methods study [36], reported on this theme. Essentially, there were three sub-themes relating to: 1) why people used the internet to seek health information; 2) concerns about using the internet; 3) and a desire to be a "well informed" patient. These relate mostly to the NPT theoretical constructs of coherence (sense making) and reflexive monitoring (appraisal). However, some of the issues raised related to Collective Action (Enacting work) when considering the effort involved in searching for information online.

Essentially, the internet was thought to be informative, but there was evidence that people had concerns about the quality of the information available on the internet, with the belief it could be contradictory at times and should be seen as provisional [38]. Contradictory information could result in additional questions arising about health and trigger a seemingly endless cycle of information seeking [38, 39].

Reasons for using the internet

Patients find the internet useful for finding out more information about their health conditions or the

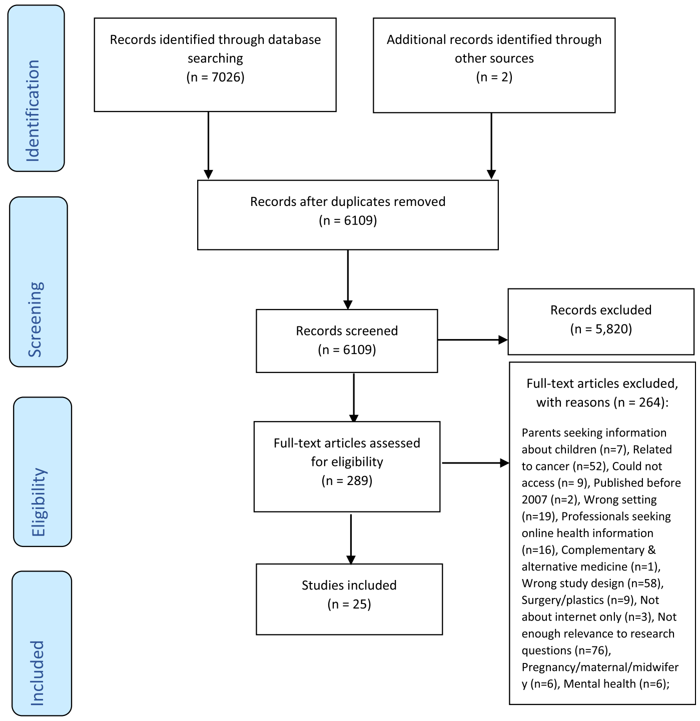


Fig. 1 PRISMA flow diagram

medications prescribed by their HCP [46]. Self-diagnosing symptoms while remaining anonymous such as by posting in online health forums was popular [37, 50] for a number of reasons. For example, people in countries where patients pay for their healthcare reported online self-diagnosis to be money saving and time efficient; they could access health information with ease for free as opposed to waiting for a healthcare appointment and then having to pay a fee [37].

Patients reported that the internet was often the first source they accessed for health information [37]. Patients found the internet convenient and that it allowed them to become more self-aware and to share their experiences within online health forums [33]. It allowed patients and the public to expand their knowledge and gain a deeper understanding of health information without involving their HCP. It was also seen as beneficial to revisit the information as many times as required for free [33]. The internet was generally seen as a tool for the treatment of non-serious medical issues or for self-diagnosis [40].

Accessibility and speed were key identified benefits of online self-diagnosing. The internet allows 24-h access, whereas obtaining an appointment with a HCP can be difficult [30, 31, 34].

> *"The Internet is really easy to use, you can use it anytime. Unlike doctors or health clinics, I can't call them and ask them at work, and after work, they are all closed. But with the Internet, you can search the information during work, and even after work, you can use your mobile phone to go on the Internet to search. I think this is really convenient and because it's the Internet, it offers you more sources and opinions."* [51].

Reasons against using the internet

There were reported concerns about the credibility, limitation and trustworthiness of online information [39, 51]. Difficulties included information overload and complex or contradictory information [47]. Searching for health information online demands time, energy, and physical effort,

Table 4 Themes and sub-themes

Theme 1: Patient perspectives on using the internet to seek health information	
Subtheme 1: Reasons for using the internet	Why patients/public use the internet for healthcare advice.
Subtheme 2: Reasons against using the internet	Why patients/public are against using the internet for healthcare advice.
Subtheme 3: The prepared patient	Why patients/public felt the importance of being prepared for consultations and more informed of their health.
Theme 2: Healthcare professionals' perspectives on and reactions to internet-informed patients	
Subtheme 1: HCP's perceptions for and against people using the internet for online health information	HCP's reasons for and against patient/public use of the internet for health information.
Subtheme 2: HCP's reactions and behaviours to internet-informed patients	The importance of reactions and behaviours from HCP's when faced with internet-informed patients.
Theme 3: Sharing online health information with healthcare professionals	
Subtheme 1: Communication	Enabling better communication within the consultation.
Subtheme 2: Bringing online health information to the consultation	The decision of whether patients/public would disclose or not disclose their online health information research to their HCP's.
Theme 4: Impact of online medical searches and diagnosis on patient-healthcare professional relationships	
Subtheme 1: Trust	Patient/public's trust in the internet and HCP's.
Subtheme 2: Role changing	Change in the HCP-patient roles.
Subtheme 3: The patient-HCP relationship	How has online self-diagnosis affecting the patient-HCP relationship.

especially for those not as familiar with technology [38, 39, 51]. One qualitative study reported that many patients (31%) believed that advice taken from the internet was not personalised to their clinical situation or based on their past medical history, preventing accurate self-diagnosis [51]. The overwhelming amount of information online can also result in the masking of credible sources [50]. This impacts patients' ability to depend on information and causes the public to find the internet less reliable than other sources of information such as HCPs [50]. However, most patients viewed their research as a complementary information source to be used alongside treatment from their HCP [30, 36, 47, 49, 50]. HCP's were thus viewed as expert guides who could aid navigation through the otherwise overwhelming quantities of health-related internet information [38]. The internet was seen to work well as a means for self-diagnosis or to find information to help ease patients' minds while awaiting doctors' appointments [30].

> *"I wouldn't trust a computer that much … any specific information like 'do this' or 'don't do that', because – even though it may be useful, I'd much rather deal with a human being, a doctor."* [31].

The prepared patient

Some people saw online self-diagnosis as a method to increase their knowledge, making them better prepared and equipped for health consultations. Having a better understanding of symptoms and conditions was thought to help them to engage more effectively with HCP's. It was also seen as a way to help them to make the most of the short time they have in consultations so they know what questions to ask [30, 38].

> *"… to go in feeling like you at least know maybe what to expect … and you know what questions to ask. Because sometimes going to the doctor is intimidating and then they … use the medical talk and you're like, 'I don't really know what that means,' so at least if you've read a little bit, you feel more prepared and can say, 'Well, what about this?"'* [33].

It was also reported that some health knowledge acquired online, was beyond the expertise of General Practitioners (GPs), causing patients to feel the need to perform research themselves to improve their self-care [31]. Patients appreciated HCP's evaluating their internet-derived health information carefully, as it helped them achieve clarity and certainty [47]. Nevertheless, Benetoli et al. [45] reported that their respondents felt that most HCP's did not appreciate online health seeking behaviours.

Healthcare professionals' perspectives on and reactions to internet-informed patients

Patient self-diagnosis and the use of the internet for health information can also impact on a HCP's role. Four qualitative [28, 38, 47, 48] and two quantitative [42–44], studies reported on these HCP's perspectives and their behaviours and reactions towards internet-informed patients. There were two major themes in relation to this: 1) HCP perceptions; and HCP reactions and behaviours when dealing with internet-informed patients. These issues related to the NPT constructs of cognitive participations (relationship work); collective action (enacting work) and reflexive monitoring (appraisal work).

Table 5 Participant quotes supporting themes

Themes	Participant quotes
People’s perspectives of online self-diagnosis and online health information seeking Coherence (CO)	**Reasons for using the internet** • “I use the Internet at home and in the office, and it is very easy, easy and most of all rapid. You lose very little time.. . And when you find what you need, then you can come back later and in a little moment I can see all the new things. So, why should I not use it?” (Caiata-Zufferey et al., 2010 [49]) **Reasons against using the internet** • “There is so much information. For example, if I wanted information on healthy diet and how to lose weight, when you search, heaps and heaps of information comes up. So it’s really difficult to decide which to use, let alone whether it’s actually suitable for me or not, or even whether it’s trustworthy.” (Chu et al., 2017 [51]). **The prepared patient** • “… to go in feeling like you at least know maybe what to expect … and you know what questions to ask. Because sometimes going to the doctor is intimidating and then they … use the medical talk and you’re like, ‘I don’t really know what that means,’ so at least if you’ve read a little bit, you feel more prepared and can say, ‘Well, what about this?’” (Rupert et al., 2014 [33]).
Healthcare professionals’ perspectives of people online self-diagnosis and online health information seeking Cognitive Participation (CP)	**HCP’s perceptions for and against people using the internet for online health information** • “I think it is a good thing for patients to have access to medical information. … But this only applies to high-quality information. Because it makes people proactive. For instance, it makes people aware of insidious health problems that are often discovered too late.” (Caiata-Zufferey & Schulz, 2012 [48]). • “For me that was the irritation, that the patient had far more trust in the computer and what they found on the web than in what I was trying to explain.” (Ahluwalia et al., 2010 [28]). **HCP’s reactions and behaviours to internet-informed patients** • “I’ve … decided that right upfront if somebody has clearly done way more reading into an area that I’d ever done I just say: ‘Wow, you know more about that than I do’ … It’s really important not to feel threatened by that information because … if you [did] … that will affect your relationship” (Townsend et al., 2015 [38]).
Sharing online health information with healthcare professionals Cognitive Participation & Collective Action (CP & CA)	**Communication** • “a huge difference … finding information, and what it means, before you go to the doctor so you can have an intelligent conversation … [and] ask them the right questions” (Townsend et al., 2015 [38]). **Bringing online health information to the consultation** • “I kind of watch the way you say it because you don’t want to offend [doctors]. I would just kind of say ‘I didn’t know whether it could be this’ … and introduce it like that.” (Rupert et al., 2014 [33]). • “I think they [HCPs] probably take you a bit more seriously when you know your stuff, because they can’t fool you around, because they know that you have the answers” (Benetoli et al., 2018 [45]).
Impact of peoples use of the internet for self-diagnosis and health information seeking on their relationship with healthcare professionals Reflexive Monitoring (RM)	**Trust** • I wouldn’t trust a computer that much ... any specific information like ‘do this’ or ‘don’t do that’, because – even though it may be useful, I’d much rather deal with a human being, a doctor (Stevenson et al., 2007 [31]). • “If you spend that last 5 min … showing them [patients] … “This is a website that you can read too. It’s got enough information but not too much and it won’t overwhelm you. This is endorsed by the Canadian Arthritis Society.” It kind of builds a level of trust and … adds a component of enrichment to the appointment … they read about it and I think they just feel a lot more like, empowered and cared for … equipped.” (Townsend et al., 2015 [38]). **Role changing** • “That’s what I’ve been experiencing by now for the last 20 years; my professional authority isn’t as sacred as it used to be. I can’t say anymore that’s it, that’s what I see, this is what we know and the patients are trusting and believe that we know best. It’s no longer like this.” (Sommerhalder et al., 2009 [47]). **The patient-HCP relationship** • “It’s just helped me have … more of a conversation with my doctor rather than just being, you know, have a one-sided, just listening. I feel like I can be more active in that interaction.” (Rupert et al., 2014 [33]) • “You just have to be really open to the fact that they’re [patients] going to tell you things you didn’t know and that’s great. “Oh I hadn’t seen that before. That might be useful for me with other clients”. So I definitely feel it’s more of a partnership …” . (Townsend et al., 2015 [38]).

HCP's perceptions for and against people using the internet for online health information

Many HCP's perceive online health information to be useful and beneficial in terms of the fact that it allows patients and the public access to a wealth of knowledge on health-related issues [28, 43, 47]. Two studies found that most nurses had positive attitudes (72.7%), to internet informed patients and that nurses previously exposed to consulting with internet-informed patients adopted more positive attitudes than those who had not been exposed [44]. Academic nurses and younger nurses reacted more comfortably to internet-informed patients compared to registered nurses and practical nurses. There was an overall positive reaction in nurses' responses to internet-informed patients [42, 44]. Such reactions were more commonly found in those with academic degrees and higher self-epistemic authority and confidence [42, 44]. Many HCP's reported that they could discuss information on a more medically grounded level with internet users than with non-internet users [47]. Some HCP's felt that patients have a right to stay well-informed and that they are more satisfied this way. They also believed patients should take responsibility for their own health and be able to make decisions, provided that they can base these decisions on high-quality sources of information [48].

> *"I think it is a good thing for patients to have access to medical information. … But this only applies to high-quality information. Because it makes people proactive. For instance, it makes people aware of insidious health problems that are often discovered too late."* [48].

However, some found online health information to be problematic, especially when patients/public interpretation of online health information was misleading or incorrect. Some physicians interpreted online health information seeking as suggesting a lack of trust in their medical expertise [28, 47]. There is also a known fear of losing control of the consultation with internet-informed patients and the feeling of being perceived as incompetent [28].

Internet-informed patients were also considered by some as potentially preventing a physician from being as effective as they could be. It can become difficult for HCP's to do their jobs efficiently as they may need to explain, interpret or suggest a conflicting opinion to the information presented from online resources [48]. Several HCP's also believed that the internet poses risks as patients may misinterpret information and this can also cause unnecessary medical visits [28, 48].

> *"For us, the doctors, the problem is that before starting you have to destroy. Patients come already with their theory and you have to dismantle it. It takes some care, and then you need to start anew."* [48].

HCP's reactions and behaviours to internet-informed patients

Patients/public found adopted reactions from HCP's such as open body language and asking open questions, making the environment more comfortable and allowing them to feel more listened to, encouraging [28]. Many HCP's agreed that it was important to show support to patients who used the internet for health information, but that such behaviours can bring associated tensions [38]. HCP's agreed on the importance of collaboration with and guidance for patients, though they struggled to find the time to do this efficiently [38].

> *"She smiled at me, she sort of sat there kind of just listening to everything, everything about her body language was just, you know, she was leaning forward, everything about it was just like really encouraging, really like, I'm here for you, I understand, I do recognise it, but don't worry, don't worry and she was able to tell me about her experiences as well."* [27].

HCP's do sometimes experience anxiety around internet-informed patients, and some may find some of the information patients bring to consultations, slightly outside their area of expertise [38].

> *"… because I think sometimes there's a fear that patients expect you to know everything and sometimes it's hard to admit that you don't know."* [28].

Sharing online health information with healthcare professionals

There were two key subthemes here: 1) Communication, which was seen as important in maintaining good relationships between patients and HCP's. 2) Bringing online health information to the consultation, which was the decision making of whether patients would share their findings with their HCP. Six qualitative studies [27, 33, 38, 39, 45, 47], five quantitative studies [29, 32, 40, 41], and one mixed methods study [36], reported on this theme. This theme maps on to the collective action and reflexive monitoring constructs of NPT.

Communication

Many studies explained that enabling better communication with HCP's was one of several reasons why patients used the internet to explore health information [27, 38, 40, 45]. Townsend et al. [38] suggested that participants felt they gained more respect from HCP's after seeking health information online as they were better prepared for their consultation and could make the most of the limited time. It also allowed them to communicate and interact better based on their increased background knowledge of the health conditions involved [27, 45].

> *"You're trying to communicate something to this person and you want the communication to be as effective as possible, so if you can show, if you can demonstrate that you understand something then that's going to move the whole process."* [27]

The HCP's in Townsend et al. (2015) study agreed and said that it also allowed the consultation to be more interactive and direct as relevant questions could be asked. HCP's also felt that patient preparation promoted more focused, effective, and efficient consultations [38].

Bringing online health information to the consultation

There were several factors affecting whether patients chose to disclose or not disclose their access of internet health information to their HCP. Imes et al. (2008), found that some patients did not talk to their HCP about online health information as they did not trust the sources online. Others found that there was not enough time to bring up their research during consultations [32, 45]. Several patients did not want to tread on the HCP's toes; such patients perceived they would be challenging the professional and did not want to question them or make them feel offended or intimidated by attempts to discuss online health information, thus interrupting the diagnostic process [27, 32, 47]. Other reasons for patients not discussing online health information research included feeling embarrassed and not wanting to be seen negatively [27, 32, 39]; such patients were concerned about HCP's reactions to their health research online and felt that they might not be listened to or that the professionals might become dismissive or uninterested [27, 32, 36, 39]. In particular, it was found patients felt that physicians would not want patients to show them how to do their jobs [39]. In the survey by Russ et al. [41], 81% of respondents never showed their internet information to their doctors, although 77.9% were interested in their HCP referring them to appropriate online health websites. Rupert et al. [33] reported that some HCP's discouraged future online health searches by indicating that the internet was an unreliable source.

> *"As soon as I said I looked it up on the internet, he sort of leaned back, and sort of, [sigh] his shoulder dropped, and he, I didn't feel that he was paying as much attention to me any more."* [27]

In contrast to these perceptions of negative reactions, some patients felt that sharing health information they found online with their HCP's could show that they had invested time and energy into the consultation; these respondents hoped this would promote them and their problems being taken more seriously [27, 45]. Positive experiences of patients sharing online health information with their doctors include all occasions when the doctor listens, acknowledges, and offers further discussion about such information [33]. Bartlett and Coulson [29] found most participants (82.2%) to be satisfied or extremely satisfied with their HCP's reactions to their participation in online support groups, while a much smaller proportion experienced negative reactions (16.2%). They found that doctors' body language was extremely important and that even a simple smile could change the dynamic of the conversation. Patients also hoped for acknowledgement of their efforts to participate in self-care [39]. Patients also brought up internet health information where they felt their research contradicted the physician's interpretation [47]. However, many patients did not use the internet to replace HCP's but rather to gain a deeper understanding of their symptoms or disease and to become more familiar with the appropriate terminology [36].

> *"Because the fact that I actually go and research things on the internet, indicates to my GP that I'm actually serious about my health and I have an interest in it myself and I'm willing to take a bit more responsibility rather than just going in like a child, listening and being told what to do. I think it means that she's more willing to treat me as an adult."* [27]

Impact of online medical searches and diagnosis on patient-healthcare professional relationships

There were three subthemes: trust; role changing and the patient-HCP relationship. Several studies have reported on the effects of this. Eight qualitative studies [27, 28, 30, 31, 46, 48, 50, 51], seven quantitative studies [32, 35, 42–44], and one mixed methods study [36], reported on this theme.

Trust

Patients felt more trust in HCP's and hoped for discussion regarding internet health information while seeking doctors' opinions [27]. Patients felt more trusting towards their GP's when they were honest about their levels of knowledge, acknowledging that generalists may not know some of the highly specific information provided online [27, 32]. Some HCP's deliberately showed respect when presented with online health information as a way of making sure patients felt listened to and respected, in the hope of encouraging patients to continue self-care [28]. Adopting this approach allows more trust to develop between the patients and HCP's [28]. One survey found that 57.5% of participants gave their physicians a perfect trust score but still used the internet after their visits to do further research [35]. Overall, health professionals were found to be more trustworthy and reliable than the internet [46].

> *"I think that certain things should be left to doctors. That's what they are there for! Even if the Internet helps us and gives us answers, the advice from my doctor gives me more confidence (…) I trust my doctor 100%"* [50].

HCP's thus appear to be the most valuable source of health information [50]. Most studies emphasised that, regardless of the popularity of online self-diagnosis, the majority of respondents valued HCP's opinions more, understood their explanations of diagnoses better, and had more trust in them [30, 50]. However, Hay et al. (2008), reported that 20% of participants went online to self-diagnose as they did not trust the diagnoses or treatment advice offered by their HCP's [36].

Role changing

Physicians have experienced changes in their roles since online health information has been introduced into consultations. Their new role can be described as acting as a partner to the patient, who is now more involved in both medical decision-making and consultation [47].

> *"That's what I've been experiencing by now for the last 20 years; my professional authority isn't as sacred as it used to be. I can't say anymore that's it, that's what I see, this is what we know and the patients are trusting and believe that we know best. It's no longer like this."* [47].

> *"You just have to be really open to the fact that they're [patients] going to tell you things you didn't know and that's great. "Oh I hadn't seen that before. That might be useful for me with other clients". So I definitely feel it's more of a partnership … [like] P2 says it's much less didactic … Like P5 said, you just put in context what they've already brought to the table."* [38].

The patient-HCP relationship

Some studies showed that HCP's perceive internet health information as damaging to the patient-HCP relationship [48], though other studies found that most were satisfied with internet-informed patients [43]. It was found that nurses with higher self-epistemic authority and confidence, were less influenced by online health information presented to them than those with lower self-epistemic authority [42]. Barnoy et al. [44] also noted that nurses with higher computer self-efficacy and lower computer apprehensiveness had more positive attitudes towards internet-informed patients.

Many participants felt that online medical searching and self-diagnosis might cause misunderstandings between them and their HCP. They did not feel they were doing this to challenge the doctors' credibility or capability in terms of diagnosis, and most patients prioritised the HCP's advice over the information from the internet. However, where the HCP's response to health information seeking is negative and disrespectful, this can seriously impact the patient-HCP relationship, and in some cases, this can lead to a patient changing their doctor or practice [27].

The results showed that most patients described their preferred role for HCP's as being open-minded about online health communities and online health information seeking. They expected feedback on the validity of their research and recommendations for online health communities, allowing for more engagement in the decision-making process by the patient in conjunction with the HCP.

> *"I was shocked out of my shoes the first time I went to the doctor, and the doctor came in and said, 'Hi, my name is Steve. I'll be your doctor, and I just want you to know that you are responsible for your health and I will make suggestions, and I would hope that you will take my suggestions, but it's up to you. Your health is your concern.' Wow! I mean it changes everything."* [34].

Patients tended to present information to the HCP to support the therapeutic relationship rather than to challenge it and Stevenson et al. [31] suggested that, based on this, HCP's should check all such information for validity.

> *"It's just helped me have … more of a conversation with my doctor rather than just being, you know, have a one-sided, just listening. I feel like I can be more active in that interaction."* [33].

Overall, the most common finding was that patients still prefer to see a HCP rather than performing online self-diagnosis and seeking internet health information. The internet is not seen as a replacement for visiting a HCP, but as offering a complimentary source of information [30, 50, 51].

Discussion

The findings of our review demonstrate that although online self-diagnosis is a growing phenomenon, the public still tend to trust the advice from a HCP over any other information source and trust in HCP's remained high. Nevertheless, the internet is viewed by patients as advantageous because of cost, accessibility, and the speed with which information can be obtained. Online resources were also viewed as valuable sources of emotional support and helpful resources to inform self-management and self-diagnosis of symptoms or conditions. It was also clear that most people did not feel that online self-diagnosis and health research had an impact on their relationship with HCP's [27, 30, 31, 50, 51].

A large proportion of people found health information obtained online to be a complementary information source, that was an adjunct rather than substitute for HCP advice and treatment [30, 36, 47, 49, 50]. These people found the method of online self-diagnosis could be reassuring while waiting for a healthcare appointment that might be some time away [30]. People used information from the internet to become better informed about their health, to prepare for their consultation, to enable them to ask better questions and to help them better understand the information given to them by HCP's [30, 38] thus helping to make consultations more productive for them.

It was clear from the findings that patients felt they had a better relationship with their HCP when they were able to discuss their online research with them and when their HCP responded positively to this. While, if people perceived a negative reaction from the HCP, this could cause distrust and embarrassment. HCP's felt that if they disagree with information that the patient highly values, this may adversely affect the patient-HCP relationship [31, 47].

HCP's reactions to people who had obtained health-related information from the internet were mixed; however, they were mostly positive. Some physicians felt that it was good that patients were looking after their own health, whereas others felt they were being challenged with information found online and that their patient had lost trust in them when they turned to the internet for help. Some also thought it could cause anxiety among patients – especially when the information was misinterpreted, and this could lead to unnecessary medical visits [28, 48].

Our findings also demonstrate that allowing patients to communicate health information obtained online with their HCP in the consultation, as well as the HCP showing that they value the patients' research, can positively affect the relationship between the two. When HCP's create an atmosphere that is open, this can encourage patients to discuss the information they have discovered; additionally the patient's perception of invading the role of the HCP or their embarrassment may be reduced, which, overall, can enhance the relationship between the patient and HCP [28, 38].

There remain outstanding research gaps. The studies included in this mixed method systematic review mainly focused on the patient's perspective of patients' use of the internet for health-related research, making our results more focused on the patient's evaluation. Fewer studies explored this from the HCP's perspective. Very few studies (2/25) included the nurse's perceptions of patients' online self-diagnosis and online health research [42, 44]. with most focusing on doctors. The majority of studies focus on the stage of researching health information, but rarely considered perceptions of or reactions to self-diagnosis and the effects of this. Many studies were generalised for all health conditions, instead of focusing on just one or two health conditions. One study in this review focused solely on multiple sclerosis patients [36]. Few studies discussed the impact of online health forums and the effects they have on an individual and their perceptions, with only two of the studies included focusing on these groups [29, 33]. Future research should explore HCPs, particularly nurses', perspectives on patients' use of the internet for self-diagnosis and health research, particularly in the context of specific health conditions and on the effects of self-diagnosis.

Evidence from existing literature has previously suggested how online self-diagnosis can introduce a negative impact on the patient-HCP relationship [48] yet in contrast findings from this mixed methods systematic review has suggested that the internet can serve as a useful resource and can potentially improve the patient-HCP relationship if used in the correct way and high-quality sources are accessed.

Strengths and limitations

Strengths of this review includes the systematic and rigorous approach taken to identify all relevant literature. A review protocol was published to PROSPERO [15] to enhance clarity and a robust thematic analysis with conceptualisation through a theoretical lens Normalisation Process Theory, to aid understanding. However, several limitations should be noted. Firstly, the search criterion that was used for this systematic review was broad in order to cover all areas that have been studied and that were associated with patient's self-diagnosis and use of the internet. Unlike clinical type studies, where each condition or intervention has one universally used term, there is no consistently used terminology to describe the patient-HCP relationship and the aspects related to it. Only English language articles were searched for, which may have reduced the number of potentially relevant studies. Secondly, sources of information such as conference proceedings, theses and abstracts were not included, which means some related studies may have been missed.

Conclusion

Although evidence has previously found that the internet can potentially have a negative impact on the patient-HCP relationship and can cause barriers in the relationship [48], this mixed methods systematic review has suggested, that patients' use of the internet for self-diagnosis and health research has the potential to positively impact the HCP-patient relationship. Patients found HCP's to be the most valued source of health information but found the internet to be a useful complementary tool [30, 36, 47, 49, 50]. Further research needs to be carried out in order to understand the effects that online health forums can have on the patient-HCP relationship so that all aspects of internet self-diagnosis can be thoroughly considered. There is also a need for more research on nurses and other AHPs perspectives of patients' use of the internet for self-diagnosis and health-related research.

Appendix

Medline search syntax

1. exp Health Knowledge, Attitudes, Practice/
2. exp Internet/
3. exp Telemedicine
4. exp Medical Informatics
5. exp Information Systems/
6. exp Cell Phone/
7. (Tele?Health or digital health or eHealth).tw.
8. (computer assisted or cyber* or "e-health" or technolog* or (electronic adj health)).tw.
9. (mobilephone) or (mobile adj phone*) or cellphone or (cell adj phone*) or smartphone or (smart adj phone*)).tw.
10. (Mobile app* or twitter or facebook or social media or search engine* or online forum).tw.
11. (iPhone or i-phone or iphone or android).tw.
12. or/1-11
13. exp Information Seeking Behavior/
14. (Diagnos* or self?diagnos*).tw.
15. ((online or web* or internet) and diagnos* or self?diagnos*)).tw.
16. (Medical seeking or medical information or medical search or medical information website or symptom check*).tw.
17. (Health literacy or health information or health search or information seeking or health information website.tw.
18. or/13-17
19. exp Professional-Patient Relations/
20. (((Doctor* or nurs* or GP* or general practitioner* or physician* or healthcare professional* or health professional* or health-care professional* or healthcare provider*) and patient*) adj5 relation*).tw.
21. (physician* perception* or physician* opinion* or doctor* perception* or doctor* opinion* or nurs* perception* or nurs* opinion* or healthcare professional* perception* or healthcare professional* opinion* or health professional perception* or health professional opinion* or patient* perception* or patient* opinion*).tw.
22. or/19-21
23. 12 and 18 and 22
24. limit 23 to (english language and yr="2007-Current")

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12911-020-01243-6.

Additional file 1.
Additional file 2.
Additional file 3.
Additional file 4.
Additional file 5.

Abbreviations

GPs: General Practitioners; HCP: Healthcare Professionals; NPT: Normalisation Process Theory

Acknowledgements

Not applicable.

Authors' contributions

AF, BJ and FM developed the study and designed the review. AF designed the search strategies with the input from BJ and FM. AF conducted the screening, quality appraisal, data extraction and analysis with the support and input from BJ and FM. AF wrote the paper with guidance and further input from BJ and FM. All authors approved the final version of the manuscript.

Funding

The authors did not receive any funding for this work.

Availability of data and materials

The data that supports the results and findings of this systematic review can be found in either the main paper or the additional supporting files.

Ethics approval and consent to participate

None sought as this was a systematic review of published studies.

Consent for publication

Not applicable.

Competing interests

The authors declare that there are no competing interests.

Author details

[1]School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences University of Glasgow, Glasgow, Scotland. [2]NHS Greater Glasgow and Clyde, Glasgow, Scotland. [3]General Practice and Primary Care, Institute of Health and Wellbeing, College of Medical, Veterinary & Life Sciences University of Glasgow, Glasgow, Scotland.

Received: 16 August 2019 Accepted: 3 September 2020

References

1. Snyder CF, Wu AW, Miller RS, Jensen RE, Bantug ET, Wolff AC. The role of informatics in promoting patient-centered care. Cancer J. 2011;17(4):211.
2. Perrin A, Duggan M. Americans' internet access: 2000–2015. Pew Res Center. 2015;26(6):1–12.
3. Carbonell X, Chamarro A, Oberst U, Rodrigo B, Prades M. Problematic use of the internet and smartphones in university students: 2006–2017. J Int J Enviro Research Public Health. 2018;15(3):475.
4. Gualtieri LN. The doctor as the second opinion and the internet as the first. CHI'09 Extended Abstracts on Human Factors in Computing Systems: ACM; 2009.
5. Castillo M. More than one third of U.S. adults use internet to diagnose medical condition. New York: CBS News; 2013. Available from: https://www.cbsnews.com/news/more-than-one-third-of-us-adults-use-internet-to-diagnose-medical-condition/.
6. MDDUS. Data explosion leading to more "worried well". Glasgow; 2015. Available from: http://www.mddus.com/news/news-digest/2015/january/data-explosion-leading-to-more-worried-well/.

7. McArdle H. 'Doctors "should not be intimidated" by patients self-diagnosing online. Scotland: Herald; 2015.
8. Warner J. Too much information can be dangerous, not empowering. Nurs Times. 2011;107(35):13.
9. Benigeri M, Pluye P. Shortcomings of health information on the internet. J Health Promot Int. 2003;18(4):381–6.
10. Koch-Weser S, Rudd RE, DeJong W. Quantifying word use to study health literacy in doctor–patient communication. J Health Commun. 2010;15(6): 590–602.
11. Hou J, Shim M. The role of provider–patient communication and trust in online sources in Internet use for health-related activities. J Health Commun. 2010;15(sup3):186–99.
12. Sabater-Galindo M, Fernandez-Llimos F, Sabater-Hernandez D, Martinez-Martinez F, Benrimoj SI. Healthcare professional-patient relationships: systematic review of theoretical models from a community pharmacy perspective. J Patient Educ Couns. 2016;99(3):339–47.
13. Fox S, Chesla C. Living with chronic illness: A phenomenological study of the health effects of the patient–provider relationship. J Am Acad Nurse Pract. 2008;20(3):109–17.
14. Moher D, Liberati A, Tetzlaff J, Altman DG, The PG. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. PLoS Med. 2009;6(7):e1000097.
15. PROSPERO. International prospective register of systematic reviews 2018 [Available from: https://www.crd.york.ac.uk/prospero/.
16. Robertson N, Polonsky M, McQuilken L. Are my symptoms serious Dr Google? A resource-based typology of value co-destruction in online self-diagnosis. Australas Mark J AMJ. 2014;22(3):246–56.
17. Endnote. EndNote | Clarivate Analytics 2018 [Available from: https://endnote.com/.
18. Partners E. Distiller SR, Systematic Review and Literature Review Software by Evidence Partners 2018 [Available from: https://www.evidencepartners.com/products/distillersr-systematic-review-software/.
19. Johnston B, McGill M, Milligan S, McElroy D, Foster C, Kearney N. Self care and end of life care in advanced cancer: literature review. J Eur J Oncol Nurs. 2009;13(5):386–98.
20. Pluye P, Gagnon M-P, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. J Int J Nurs Studies. 2009;46(4):529–46.
21. Hong QN, PLUYE P, FÀBREGUES S, BARTLETT G, BOARDMAN F, CARGO M, et al. Mixed methods appraisal tool (MMAT), version 2018. 2018.
22. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. J Handbook of research methods in health social sciences; 2018. p. 1–18.
23. May C, Finch T. Implementing, embedding, and integrating practices: an outline of normalization process theory. Sociology. 2009;43(3):535–54.
24. May CR, Cummings A, Girling M, Bracher M, Mair FS, May CM, et al. Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. Implement Sci. 2018;13(1):80.
25. Mair FS, May C, O'Donnell C, Finch T, Sullivan F, Murray E. Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review. Bull World Health Organ. 2012;90(5):357–64.
26. O'Connor S, Hanlon P, O'Donnell CA, Garcia S, Glanville J, Mair FS. Understanding factors affecting patient and public engagement and recruitment to digital health interventions: a systematic review of qualitative studies. BMC Med Informatics Decision Making. 2016;16(1):120.
27. Bowes P, Stevenson F, Ahluwalia S, Murray E. 'I need her to be a doctor': patients' experiences of presenting health information from the internet in GP consultations. J Gen Pract. 2012;62(604):e732–e8.
28. Ahluwalia S, Murray E, Stevenson F, Kerr C, Burns J. 'A heartbeat moment': qualitative study of GP views of patients bringing health information from the internet to a consultation. Br J Gen Pract. 2010;60(571):88–94.
29. Bartlett YK, Coulson NS. An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. J Patient Educ Couns. 2011;83(1):113–9.
30. Donnelly LS, Shaw RL, van den Akker OB. eHealth as a challenge to 'expert' power: a focus group study of internet use for health information and management. J R Soc Med. 2008;101(10):501–6.
31. Stevenson FA, Kerr C, Murray E, Nazareth I. Information from the internet and the doctor-patient relationship: the patient perspective – a qualitative study. J BMC Family Pract. 2007;8(1):47.
32. Imes RS, Bylund CL, Sabee CM, Routsong TR, Sanford AA. Patients' reasons for refraining from discussing internet health information with their healthcare providers. J Health Commun. 2008;23(6):538–47.
33. Rupert DJ, Moultrie RR, Read JG, Amoozegar JB, Bornkessel AS, O'Donoghue AC, et al. Perceived healthcare provider reactions to patient and caregiver use of online health communities. J Patient Educ Couns. 2014;96(3):320–6.
34. Macias W, McMillan S. The return of the house call: The role of internet-based interactivity in bringing health information home to older adults. Health Commun. 2008;23(1):34–44.
35. Bell RA, Hu X, Orrange SE, Kravitz RL. Lingering questions and doubts: online information-seeking of support forum members following their medical visits. Patient Educ Couns. 2011;85(3):525–8.
36. Hay MC, Strathmann C, Lieber E, Wick K, Giesser B. Why Patients Go Online: Multiple Sclerosis, the Internet, and Physician-Patient Communication. Neurologist. 2008;14(6):374–81.
37. Fiksdal AS, Kumbamu A, Jadhav AS, Cocos C, Nelsen LA, Pathak J, et al. Evaluating the process of online health information searching: a qualitative approach to exploring consumer perspectives. J Med Internet Res. 2014; 16(10):e224–e.
38. Townsend A, Leese J, Adam P, McDonald M, Li LC, Kerr S, et al. eHealth, participatory medicine, and ethical care: a focus group study of patients' and health care providers' use of health-related internet information. J Med Internet Res. 2015;17(6):e155.
39. Silver MP. Patient perspectives on online health information and communication with doctors: a qualitative study of patients 50 years old and over. J Medical Internet Res. 2015;17(1):e19.
40. Haluza D, Naszay M, Stockinger A, Jungwirth D. Digital natives versus digital immigrants: influence of online health information seeking on the doctor–patient relationship. J Health Commun. 2017;32(11):1342–9.
41. Russ H, Giveon SM, Granek Catarivas M, Yaphe J. The effect of the internet on the patient-doctor relationship from the patient's perspective: a survey from primary care. J IMAJ-Israel Med Assoc J. 2011;13(4):220.
42. Barnoy S, Volfin-Pruss D, Ehrenfeld M, Kushnir T. Self-epistemic authority and nurses' reactions to medical information that is retrieved from Internet sites of different credibility. Nurs Health Sci. 2011;13(3):366–70.
43. Giveon S, Yaphe J, Hekselman I, Mahamid S, Hermoni D. The e-patient: a survey of israeli primary care physicians' responses to patients' use of online information during the consultation. Israel Med Assoc J. 2009;11(9):537–41.
44. Barnoy S, Volfin-Pruss D, Ehrenfeld M, Kushnir T. Factors affecting nurses' attitudes in Israel toward patients who present them with internet medical information. Nurs Outlook. 2008;56(6):314–21.
45. Benetoli A, Chen T, Aslani P. How patients' use of social media impacts their interactions with healthcare professionals. J Patient education counseling. 2018;101(3):439–44.
46. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. J Med Internet Res. 2014;16(12):e262–e.
47. Sommerhalder K, Abraham A, Zufferey MC, Barth J, Abel T. Internet information and medical consultations: experiences from patients' and physicians' perspectives. Patient Educ Couns. 2009;77(2):266–71.
48. Caiata-Zufferey M, Schulz PJ. Physicians' communicative strategies in interacting with internet-informed patients: results from a qualitative study. Health Commun. 2012;27(8):738–49.
49. Caiata-Zufferey M, Abraham A, Sommerhalder K, Schulz PJ. Online Health Information Seeking in the Context of the Medical Consultation in Switzerland. Qual Health Res. 2010;20(8):1050–61.
50. Mendes Á, Abreu L, Vilar-Correia MR, Borlido-Santos J. "That should be left to doctors, That's what they are there for!"—exploring the reflexivity and Trust of Young Adults When Seeking Health Information. Health Commun. 2017;32(9):1076–81.
51. Chu JT, Wang MP, Shen C, Viswanath K, Lam TH, Chan SSC. How, When and Why People Seek Health Information Online: Qualitative Study in Hong Kong. Interactive J Med Res. 2017;6(2):e24–e.

Publisher's Note

Appendix 25: Publication in Journal of Advanced Nursing (Chapter Six: Phase two of Heart Failure Online Health Forums)

Received: 13 February 2021 | Revised: 26 June 2021 | Accepted: 29 July 2021
DOI: 10.1111/jan.15009

ORIGINAL RESEARCH:
EMPIRICAL RESEARCH – QUALITATIVE

An analysis of the diagnostic accuracy and peer-to-peer health information provided on online health forums for heart failure

Annabel Farnood[1] | Bridget Johnston[1,2] | Frances S. Mair[3]

[1]Nursing and Healthcare, School of Medicine, Dentistry & Nursing, University of Glasgow, Glasgow, UK
[2]NHS Greater Glasgow & Clyde, Glasgow, UK
[3]General Practice and Primary Care, Institute of Health and Wellbeing, University of Glasgow, Glasgow, UK

Correspondence
Annabel Farnood, Nursing and Healthcare, School of Medicine, Dentistry & Nursing, University of Glasgow, Glasgow, UK.
Email: a.farnood.1@research.gla.ac.uk

Funding information
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Abstract

Aims: To examine the accuracy of diagnostic responses and types of information provided on online health forums.

Design: Qualitative descriptive study.

Methods: This paper reports the findings of a thematic analysis of peer responses to posts included on heart failure online health forums, to understand the quality and types of information provided. Responses posted between March 2016 and March 2019 were screened, collected and analysed thematically using Braun & Clarke. Themes were conceptually underpinned by Normalization Process Theory. Responses were assessed for quality against the NICE and SIGN guidelines to determine whether they were evidence based or not.

Results: The total number of responses collected for analysis was 639. Five main themes were identified: diagnostic, experiential, informational, peer relations and relationships with healthcare professionals. Out of 298 diagnostic responses, 5% were guideline evidence-based and 6% had information that were partly evidence-based. Non-evidence based and potentially dangerous responses were 10%. Experiential responses were 10%; 23% included advice that was not supported with any clinical evidence; and 46% signposted users to other online references/healthcare professionals.

Conclusion: Online health communication largely focuses on provision of experiential responses to assist those in need of pre- or post-diagnosis advice and support. However, there is evidence of inaccurate information provision which suggests the use of a moderator would be beneficial.

Impact: This study suggests heart failure online health forums are a source of support, however, there are potential risks. Increasing nurses and other health care professional's awareness of online health forums will be important. Additional training is needed to help them learn more about patient's use of online health forums, to gain a better understanding about the types of information sought, and how best to address such knowledge deficits. Healthcare systems must ensure sufficient time and resources are available to meet information needs for people with heart failure.

KEYWORDS
health communication, health informatics, healthcare information systems, heart failure, information seeking behaviour, nurses, nursing, online communities, online health forums, self-diagnosis

1 | INTRODUCTION

Heart failure is a major public health challenge and described as an epidemic (Cowie, 2017). It is a serious condition that is associated with high levels of health care utilization (Escobar et al., 2020). Heart failure continues to have a poor 5 year survival (45.5%), despite many advances in both pharmacological and non-pharmacological therapies (Taylor et al., 2019). It is estimated that there are around 900,000 people in the UK and 26 million people worldwide, living with heart failure (Apps & Phelan, 2018; Chew et al., 2019).

People with heart failure are known to have many unmet needs, particularly information needs relating to diagnosis, treatments and when to seek help (Browne et al., 2014). People with heart failure have access to different information sources such as general practitioners, cardiologists, heart failure specialist nurses, district nurses and practice nurses (Brennan, 2018). In between waiting for health care professional (HCP) appointments, many people resort to the internet as a source of health information. They may use this before or after an appointment to find out more information about heart failure, or to search for symptoms (Robertson & Harrison, 2009).

Online health forums have become an increasingly common way to obtain information and support health-related issues (Lin et al., 2015). For many people, the internet is now a major source of health information (Daraz et al., 2019). It is, however, important to know how accurate the diagnostic advice on these online health forums are, and the types of information they provide. This may impact the nurse and HCP-patient relationship and influence approaches to health care delivery.

The nursing profession continues to evolve and specialized roles such as heart failure nurses and advanced nurse practitioners are becoming more commonplace. It is therefore essential for nurses to be made aware of patient's use of online health forums as an information source and understand how and why people use them.

2 | BACKGROUND

The National Institute for Health and Care Excellence (NICE) guidelines define heart failure as 'a complex syndrome in which the ability of the heart to maintain the circulation of blood is impaired as a result of a structural or functional impairment of ventricular filling or ejection' (NICE, 2017).

Online health forums can be a more engaging, conversational and investigational alternative to web searches on available search engines (Nguyen et al., 2020). However, there is a concern about the accuracy of health information provided online (Coulson et al., 2007; Plinsinga et al., 2019).

Findings from a recent mixed methods systematic review suggest that HCP's have concerns about the quality of health information that is being accessed and the potential for people to be misinformed (Farnood et al., 2020). Previous research also suggests that misinformation from the internet can add pressure to the appointment, constraining the HCP's time (Zolnierek & DiMatteo, 2009). If a person has become misinformed from online health information, the HCP may need to spend time and effort correcting misunderstandings (Lee et al., 2015; Lu et al., 2018; Tan & Goonawardene, 2017).

To date, online health forum studies have predominately focused on mental health conditions (Cohan et al., 2017; Kummervold et al., 2002; Prescott et al., 2017; Pruksachatkun et al., 2019). Previous research has investigated other conditions such as breast cancer, type 2 diabetes and stroke (Chen, 2012; De Simoni et al., 2016). The existing literature around heart failure and online health forums is limited and focuses on heart failure medications (Liu et al., 2014; Sarrazin et al., 2014) and assessing the online health forums for changes in health behaviours (Lindsay et al., 2009). No previous literature has been found assessing the quality of information provided on heart failure online health forums or the types of information provided. Due to the scarcity of previous research on online health forums and heart failure, we undertook qualitative research to gain a preliminary understanding of the quality and types of information provided on online health forums focusing on heart failure.

3 | THE STUDY

3.1 | Aims

We aim to understand the types of information people discuss when engaging with online health forums for heart failure and explore the quality of diagnostic advice provided. The main research questions to be addressed are:

- To what degree is the diagnostic advice provided on heart failure online health forums evidence based?
- What type of information is provided on online health forums for heart failure?

3.2 | Study design

A qualitative descriptive approach (Sandelowski, 2000) was undertaken to describe this phenomenon as no previous research was found prior to this study. We examined responses to discussion posts on online health forums for those with heart failure or those looking to understand whether their symptoms might suggest a diagnosis of heart failure. We used thematic analysis and conceptualized our data through a normalization process theory (NPT) lens to help us understand and evaluate the types of information sought and provided. NPT is a useful framework to explain and understand self-management (Gallacher et al., 2011, 2013) and how people implement new interventions into their everyday routines through four constructs: coherence; cognitive participation; collective action; and reflexive monitoring (May et al., 2018).

3.3 | Sample participants

Widely used internet search engines, Google, Yahoo and Bing, were used to identify online health forums. The search terms used were 'heart failure online support forums' and 'online health discussion forums for heart failure'. The first two pages of results from each search engine were analysed as it has been reported that the typical internet user does not browse further than the second page (Pan et al., 2007). Responses were screened accordingly to the eligibility criteria, and online health forums were selected according to the name and content (see Figure 1). There was no interaction or participation from the researchers on the forums. Only patient and public discussion forums were included as we examined people's use of the internet as opposed to forums used by HCPs. Only forums that were about heart failure or discussing heart failure were included. All forums had the same purpose of being an online community for those with heart failure or looking to diagnose or seek further information about heart failure. There was no geographical limit to the forums. Posts were browsed by subject title, date and relevancy to heart failure. If they met the inclusion criteria, they were collected for analysis (see Table 1).

3.4 | Data collection

Internet discussion forum posts that were considered to be part of the public domain were examined. Responses posted between March 2016 and March 2019 were collected from each forum. This timeframe was chosen as the Scottish Intercollegiate Guide Network (SIGN) guidelines for heart failure were last updated in 2016. Data were not collected if it stated that the person was under the age of 18. The SIGN and NICE guidelines only apply to those over the age of 18 (NICE, 2018; SIGN, 2016). Posts were only collected if they discussed issues related to heart failure (Table 1). Usernames were not extracted from the data; only the content of the post was included. All identifying information was deleted to protect the anonymity of the forum's participants. We only analysed health forums that were publicly available and did not require a login to review the posts.

Socio-demographic data was collected but limited to what the online members wanted to share, for example: location, gender and age.

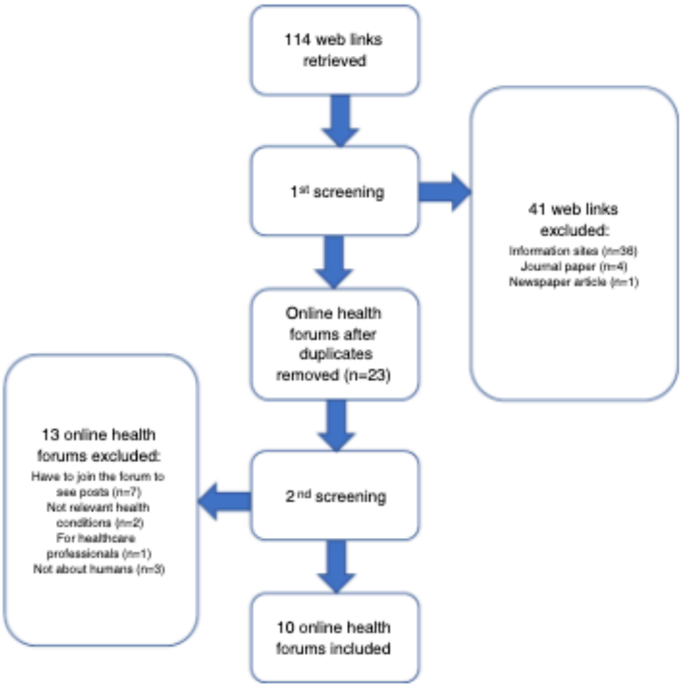


FIGURE 1 Search strategy

TABLE 1 Eligibility criteria

Inclusion	Exclusion
• Search engines: Google, Yahoo and Bing. • Only the first two result pages of each search engine were analysed. • Selected forums must be about heart failure. Can be about 'heart diseases', if it includes discussion on heart failure. • Discussion posts will be analysed from the year 2016–2019.	• Exclude search engines that do not meet the inclusion criteria. • Exclude posts before 2016. • Forums that are not health related. • Forums that do not allow patient engagement. • One-word responses. • If the user states they are under the age of 18, the response will be excluded.

TABLE 2 Normalization process theory coding frame for people responding to discussion posts

Coherence (sense-making work)	Cognitive participation (relationship work)	Collective action (enacting work)	Reflexive monitoring (appraisal work)
Differentiation	*Initiation*	*Interactional workability*	*Systemization*
Using online health forums to gain and understand information.	The peer-to-peer engagement in the groups and seeking assurance.	Communicating complex health issues online with peers.	Determining the benefits and risks of online self-diagnosis and health information seeking on online health forums.
Communal specification	*Enrolment*	*Relational integration*	*Communal appraisal*
Responding to posts requesting further information to gain a better understanding of the individuals health situation.	Peers reactions and behaviours towards other peers' comments.	The influence of sharing health advice with others sharing similar issues and gaining support. Maintaining a level of confidence and accountability to continue using the online forums.	Working together on the internet to determine and evaluate the value of certain treatments. To aid decision-making on treatments.
Individual specification	*Legitimation*	*Skillset workability*	*Individual appraisal*
People achieving an understanding of their diagnosis and its implications through health information gained via the internet through peers.	Respondents sharing their own experiences to the posts on the online health forum.	The effect of using online information on roles and responsibilities of members of the public or HCPs. The impact online information has on the decision-making process.	Distributing information on the internet to determine how effective their treatment is and to provide or gain a diagnosis.
Internalization	*Activation*	*Contextual integration*	*Reconfiguration*
Peoples understanding of using the internet to self-diagnose and knowing if this is their preference or if they value the role of the HCP consultations instead.	Communicating effectively with peers by expressing relatability and assurance.	Recommending the individual to seek professional medical attention or to be seen by an HCP. Offering health advice by referring to other online resources.	Individuals decision-making process of how effective online health forums are for diagnosing and seeking health information for heart failure. The impact this has on relationships with their HCP.

TABLE 3 Frequency count of the quality of evidence assessment (based on the John Hopkins nursing evidence-based practice guidelines)

Total number of responses that were diagnostic	*N* = 298
Level 1. High-quality evidence: Aligned with SIGN or NICE guidelines for heart failure—responses that contained information that can be found in the SIGN or NICE clinical guidelines for heart failure (does not have to include reference to guidelines)	*N* = 15 (5%)
Level 2. Good quality evidence: Responses that included information that was supported by a mix of high- and moderate-quality evidence such as the BHF	*N* = 19 (6%)
Level 3. Evidence-based: Responses that included information that were not in the guidelines but were supported by some reliable sources but appeared inconclusive	*N* = 0 (0%)
Level 4. Opinion: No advice given but opinion provided to help inform the next steps by signposting users to their HCP or other information sources	*N* = 136 (46%)
Level 5a. Low quality (experiential): Responses that offered advice based on an individual's personal experience but included no evidence	*N* = 29 (10%)
Level 5b. Low quality (lack of evidence): Advice provided that was not deemed potentially dangerous but had no supporting evidence	*N* = 70 (23%)
Level 5c. Non evidence-based and potentially harmful: Includes responses including information that is inconsistent with the national guidelines or high-quality/good evidence of best practice and may be harmful	*N* = 29 (10%)

3.5 | Ethical considerations

This study was granted ethics approval from the College of Medical, Veterinary and Life Sciences, University of Glasgow ethics committee (200180115). Informed consent was not sought, as data was collected from open access websites that were already in the public domain. We have not included the names of the forums to ensure anonymity for the members.

3.6 | Data analysis

Phase one of data analysis involved thematic analysis of the responses to understand what types of information were provided on these forums based on the methodology outlined by Braun and Clarke (2012). Analysis was conducted by first author (AF), a doctoral student at the University of Glasgow and registered nurse, in collaboration with the interprofessional authorship team (BJ, FM) who bring extensive clinical and academic expertise in chronic health management and qualitative health research.

Thematic analysis (Braun & Clarke, 2012) was undertaken as we were interested in understanding the nature of the responses to the questions that are posted online, and such analysis supports identification of semantic elements of texts or what they mean (Braun & Clarke, 2012). The data were read and re-read to ensure thorough analysis. Extracted data were coded to initial themes generated from the data. The initial themes were then compared and grouped into themes and subthemes.

Once themes were identified, they were mapped onto the constructs of NPT (Table 2). At this point, the constructs of NPT were cross referenced against the derived themes to see if NPT could illuminate the themes from the data. This stage was performed to ensure that themes were directly derived from the data and the data was not forced to fit the constructs of NPT. NPT was used as a theoretical lens with which to interrogate the findings.

In Phase 2 we analysed the quality of evidence of responses. We used the SIGN (SIGN, 2016) and the NICE (NICE, 2018) guidelines for heart failure symptoms and diagnosis as the gold standard with which to judge the quality of the information being provided to patients through the online health forums and compared the extracted content. The British Heart Foundation (BHF) (BHF, 2020), provides further lay information outside the scope of the guidelines and appeared the most often in our search strategy; therefore, we also used the BHF website to compare the accuracy of responses, as people commonly used this source.

As the study was conducted in the UK and considering the types of responses and scale of the study, NICE and SIGN guidelines were deemed most appropriate to be used after being carefully compared with the American Heart Association guidelines (AHA, 2017) to ensure similarity and appropriateness. If the content was not displayed in the guidelines, we looked at the BHF website (BHF, 2020) as 'good evidence', as this was a reliable and recognized information source that most frequently appeared in our search results.

We adopted the hierarchy of evidence, based on the John Hopkins nursing evidence-based practice guidelines (Dang & Dearholt, 2017), as a guidance to assess the levels and quality of evidence provided in the responses. The quality of evidence was categorized between levels one to five (see Table 3). High quality evidence included those aligned with the NICE and SIGN guidelines and good quality evidence included information in the BHF website. Level four included opinions of people signposting others to help inform people's decision-making. Level five was graded low quality evidence and split into three categories—lack of evidence, experiential or included potentially harmful responses that were inconsistent with the national guidelines or high quality and good evidence.

3.7 | Validity and reliability/rigour

The appropriateness of the themes identified were verified by two researchers. Five themes were identified from the thematic analysis and then mapped onto the constructs of the NPT framework. NPT provides a conceptual vocabulary for rigorous studies of self-management (Gallacher et al., 2011, 2013) and implementation processes (May et al., 2018).

Each item of extracted data was coded independently through thematic analysis. During the process, common themes were identified and there was an indication of data saturation. The codes were analysed in a framework and then mapped onto the constructs of NPT. Any data that fell outside the framework was noted to ensure there was no 'shoe-horning' of themes into the framework.

The consolidated criteria for reporting qualitative research (COREQ) was adhered to when reporting the results (Tong et al., 2007).

4 | FINDINGS

4.1 | Screening

The search criteria returned 114 web results in total. Seventy-three were online health forums and the remaining 41 were excluded as they did not meet the inclusion criteria. Ten of the online health forums were eligible for the study (Figure 1). Four forums were identified by Google, six by Yahoo and Bing did not identify any additional health forums that were not already included from the other search engines.

4.2 | Data collected

Ten online health forums from the UK (*n* = 6) and USA (*n* = 4) were included, and the total number of responses collected for analysis was 639 (from 204 original posts). In some threads, each member posted on average two or three comments, although some members were particularly active (usually the original poster). The frequency count of response in each theme and sub-theme are presented in Table 4.

Gender was specified in 51/639 of the response posts. Of these, 39 were females (76%) and 12 males (24%). The members ranged from people seeking a diagnosis, to those already diagnosed sharing their experiences, providing advice or gaining support. Geographical location was mentioned in 49/639 of the response posts (see Table 5).

5 | MAIN THEMES

Five broad themes with sub-themes were identified: diagnostic responses, experiential, informational, peer relations and relationship with HCP's (Table 4). Each theme was mapped onto the core constructs of the NPT framework (Table 2).

The themes have been illustrated with paraphrased extracts from the response posts. Direct quotations have been limited as these may allow the data to be tracked to the original source which will compromise anonymity. Therefore, we have only included one quotation per sub-theme. The themes have been developed from quotations across the sources of data, highlighting similar topic areas identified from the heart failure forums.

TABLE 4 Frequency count of responses in each theme

No. of responses in each theme	No. of responses in each sub-theme
Diagnostic responses (n = 298) Collective action (CA) & reflexive monitoring (RM)	- Evidence-based nature of the diagnostic responses (*n* = 162) - Signposting services (*n* = 136)
Experiential (n = 135) Cognitive participation (CP)	- Sharing personal experiences (*n* = 68) - Experiential supportive information (*n* = 67)
Informational (n = 101) Coherence (CO) & cognitive participation (CP)	- Finding out more information (*n* = 59) - Giving advice (*n* = 35) - Advising against internet (*n* = 7)
Peer relations (n = 84) Cognitive participation (CP) & reflexive monitoring (RM)	- Peer conflict (*n* = 14) - Support (*n* = 70)
Relationship with HCP's (n = 21) Cognitive participation (CP) & reflexive monitoring (RM)	- Distrust/conflict with HCP's (*n* = 16) - Supportive of HCP's (*n* = 5)

NPT has helped highlight the important aspects of the types of information people seek on heart failure online health forums: diagnostic advice (collective action—enacting work; reflexive monitoring—appraisal work), support, sharing experiences and confirmation that beliefs or concerns were legitimate (cognitive participation—relationship work), seeking information (coherence—sense-making work; cognitive participation—relationship work), building peer relationships (cognitive participation—relationship work; reflexive monitoring (appraisal work), and relationships with HCP's (cognitive participation—relationship work; reflexive monitoring—appraisal work).

TABLE 5 Location of responders

Country	No. of responses (*n* = 49)
UK	*N* = 16 (33%)
USA	*N* = 16 (33%)
Australia	*N* = 10 (20%)
Canada	*N* = 4 (8%)
France	*N* = 2 (4%)
Pakistan	*N* = 1 (2%)

5.1 | Diagnostic responses

A large proportion of the responses was of a diagnostic nature. Direct diagnostic responses (*n* = 291) were compared against the NICE and SIGN guidelines and were measured for quality of evidence based on the John Hopkins evidence-based practice guideline (Dang & Dearholt, 2017) (Table 3). Figure 2 provides a detailed illustration of the obtained results. These relate mostly to the NPT theoretical construct of collective action (enacting work) as this is the process of communicating health information with peers and recommending resources and information. The reflexive monitoring construct (appraisal work) is also related as it involves the distribution of information that leads to decision-making (Table 2).

5.1.1 | Evidence-based nature of the responses

Only 5% (*n* = 15) of the obtained responses were evidence-based and aligned with the SIGN and NICE guidelines. Another 6% (*n* = 19) presented information that was available on the BHF website or partly evidence-based information. Importantly, 10% (*n* = 29) of the responses were non-evidence based and potentially harmful. No responses (0%) provided inconclusive evidence. The majority of responses lay in between low-quality categories and opinions, for

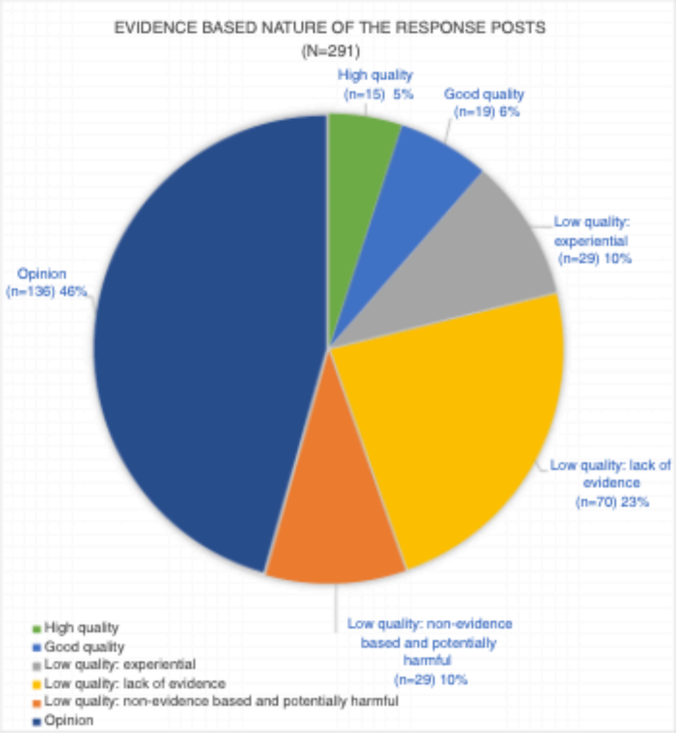


FIGURE 2 Evidence-based nature of the responses

example: experiential responses 10% ($n = 29$), innocuous advice unsupported by clinical evidence 23% ($n = 70$) and signposting services 44% ($n = 136$) (Table 3). Table 3 presents the levels of evidence for the responses. Figure 2 illustrates the results of rating the quality of evidence of responses.

Many responders stated they were not HCPs but advised the individual to seek medical attention. In these replies, a medical diagnosis or opinion was also given. This was deemed to be evidence-based, if it provided information compatible with that found in the NICE or SIGN guidelines. In addition, the offered advice was considered as evidence-based if reported on the BHF website, even though it could not be found in NICE or SIGN guidelines.

> Sorry to read about what you are going through. I would suggest visiting your primary care doctor and ask to be referred to a cardiologist. Also, many things can cause chest pain that are not heart related.

Very few posts shared information about research, and none mentioned ongoing research. This may suggest that research sources are not rapidly and easily accessible to the public. Diagnostic advice was offered based on their own experiences of the signs, symptoms or questions asked by the user (10%). While this type of diagnostic advice may be supportive to the posting individual, it does not represent good and reliable advice since no scientific evidence was shared.

> It sounds like the same thing I had. The doctors called it congestive heart failure. Sadly I need to say if this is the case, you will need a lot of heart care.

Non-evidence based and potentially harmful replies included those offering a confirmed diagnosis to the individual ($n = 29$, 10%). This diagnosis was incorrect, not supported by information included in the NICE, SIGN or BHF guidelines, and did not contain any underpinning evidence to support the advice given. Many posts signposted users to their HCP or other web sources including informational websites, other more appropriate online health forums and charity or university websites. Out of 46 website suggestions, 41 were deemed reliable, and 5 were unreliable sources and potentially dangerous.

> Echo and BNP are the tests for heart failure. HF with preserved ejection fraction would also show up on echo.

5.1.2 | Signposting services

The majority of responses ($n = 136$, 46%) provided opinions that informed the posting individual to take action and visit their HCP ($n = 90$) or to visit other web sources ($n = 46$) and were graded as level four evidence (Table 3) as they provided no evidence but were responses based on opinion (Figure 2). Usually, this suggestion was given when the responder perceived that the query departed significantly from their knowledge spectrum and required specialist advice. In addition, the responders acknowledged their inability to provide sound diagnostic suggestions for individuals perceived to be in need of urgent attention and appropriate testing to determine their cause for concern. When individuals experienced high levels of anxiety, usually responders offered psychological support simultaneously suggesting they seek professional help to receive appropriate care to ease their worries.

When professional help was suggested, a variety of terminologies were used, and different HCP types were recommended. Most responders urged the individual to visit a doctor. A visit to the cardiologist or doctor represented the most frequent recommendation, followed closely by an appointment with the general practitioner/primary care practitioner. While mentioned, nurses, even heart failure specialist nurses, were not as commonly endorsed. Other recommended services included pharmacists, social services and counsellors. When the responder perceived the presented scenario to be an emergency situation, hospital services were strongly advised. Different terminologies were used for hospital settings, including going to the emergency room or accident and emergency, based on the responder's geographical location (see Table 6).

Consistently, most replies offered advice but simultaneously recommended that the person should visit their HCP for urgent attention, testing, and further support or to receive the appropriate care.

> 'I think you should go to the emergency room for a second opinion'.

We analysed the websites content and link reliability, in the event of web sources being suggested through the diagnostic advice process. A total of 46 replies recommended other web sources. It was discovered that 41 of these websites were reliable and 5 were unreliable.

Charity websites ($n = 22$), such as the American Heart Association or BHF were the most frequently recommended. Individuals were also directed towards other online health forums ($n = 7$), presumed to be more suitable for their needs, information websites ($n = 10$) such as NHS, and university web links ($n = 2$).

Unreliable sources included an uncredited YouTube link for a channel belonging to an unknown user ($n = 1$), and a Wikipedia page ($n = 1$), untrustworthy by definition since the reported information is subject to change implemented by anyone. Other unreliable sources included web links that did not work or pages that could not be found ($n = 3$).

5.2 | Experiential responses

Experience sharing was a common occurrence identified in the responses (Figure 2) but graded as level five evidence (low quality) as they provided no evidence and were based on people's experiences (Table 3). A significant number of people felt they could relate to the individuals experience. This led them to share their own and created a community where they did not feel alone coping with their conditions. By sharing their experiences, people offered support to each other as result. This relates to the NPT construct of cognitive

TABLE 6 Frequency of mentions of peers advising others to healthcare professional services and terminologies used

Healthcare professionals	**Frequency of mentions (*N* = 90)**
Doctors	
Cardiologist	$N = 25$
Doctor	$N = 25$
General practitioner	$N = 7$
Primary care practitioner	$N = 3$
Physician	$N = 3$
Primary care doctor	$N = 2$
Neurologist	$N = 1$
GI doctor	$N = 1$
Nurses	
Heart failure nurse	$N = 2$
Nurse	$N = 1$
BHF nurse	$N = 1$
Other healthcare professions	
Heart failure team	$N = 1$
Social services	$N = 1$
Pharmacist	$N = 1$
Counsellor	$N = 1$
Hospital services	
Emergency room	$N = 7$
Hospital	$N = 6$
Accident & emergency	$N = 2$

participation (relationship work) due to people engaging in discussions with peers and sharing their experiences. This type of information sharing promotes relationship work and helped people to legitimize concerns or problems (Table 2).

5.2.1 | Sharing personal experiences

Often, responders shared their own experiences when they felt able to relate to what the individual discussed. Responders shared their experience of the difficult process undertaken to attain a diagnosis, of symptoms and conditions suffered, of treatment and medications received, and of relationships. Usually, people reacted well when the responder shared their own experiences, since this made them feel part of a community and less alone. Frequently, individuals wanted to share and compare experiences. This generated suggestions in changes of approach for the fellow peer to use.

> I was going to post something similar. I've been back and forward to the Drs and hospital for months with similar symptoms.

5.2.2 | Sharing supportive experiences

Support through experience was proven to be beneficial, since people demonstrated to the user that they are not alone. The responder has previously experienced something similar, and he/she reassures the individual that there is hope. A key difference exists between sharing personal experiences and sharing supportive experiences, since the former exercises the powerful ability to ensure that individuals understand they are not alone with their illness, preventing condition isolation.

> *I'm sorry about what you're dealing with, I suffer the same things. If you need someone to talk to who's similar, let me know and I'll talk with you. It's always nice to know you're not alone.*

5.3 | Informational responses

Informational responses provided substantial intelligence not with the aim to diagnose, but with the objective of offering knowledge to answer a question and were commonly distributed in the responses. These included advice around the condition, lifestyle changes, suggestions on medication and more. These relate mostly to the NPT theoretical construct of coherence (sense-making work) as respondents sought to find out more information by asking the user follow-up questions to provide more efficient advice. Cognitive participation (relationship work) is another construct related to this theme as the sense-making work begins a discussion process where information is being shared between peers, providing assurance for one another (Table 2).

5.3.1 | Finding out more information

Finding out more information included responses following requests for more expertise from the individual who posted, while answering their initial questions. These replies were classified as informational, since they provided knowledgeable advice while requesting more facts at the same time. By finding out further information, a sense of interest in the individual's situation was triggered, contributing to the establishment of a relational bond between participants. Usually, after posting a query, the individual expressed gratitude towards the user who responded, who helped finding a satisfactory conclusion to their questions while asking further details about their situation and providing additional informational advice.

> What does the chest pain feel like? I'm not a doctor but does it hurt when you breathe in?

5.3.2 | Giving advice

A significant difference exists between providing advice around a condition and providing diagnostic information. This divergence recognizes that providing advice does not equate with giving a direct diagnosis to the individual. Therefore, advice was offered in an informational way steering the individual towards services and further resources. Users who responded included information that answered the question directly and made suggestions on what the individuals could do next.

> Stress is a big part of the equation. Relaxing is the cure and one excellent way to do that is exercise. Keep it up!

5.3.3 | Advising against internet advice

Some responders felt that individuals should not rely on the internet or searching Google to determine their health condition and should not receive a diagnosis online. Responders suggested this could generate unnecessary stress and worry because of the overwhelming amount of retrievable information, navigation difficulties and the problem of identifying reliable sources. The individuals themselves suggested that this practice could be unreliable and were aware that they should visit a trained HCP instead.

> The internet will only give a broad diagnosis. Be cautious when researching on the web.

5.4 | Peer relations

We examined patient's communication which led to relationship building responses. A community is characterized and arises from posting in online health forums. In these communities, relationships become established, since the main purpose is to provide support for individuals in their time of need. We discovered that many responses were supportive, but others led to tension and conflict. This relates mostly to the NPT constructs of cognitive participation (relationship work) as this is the peer-to-peer engagement process, as well as reflexive monitoring (appraisal work). The peer-to-peer engagement process leads to peers working together to collectively make a decision (Table 2).

Usually, supportive responses let the individual know that they are not alone, and they have found support in the community. Consequently, the user posted regular updates and found comfort from like-minded people that replied and related to them. Some supportive responses included similar experiences with a positive outcome, increasing hope for the individual.

> You're not alone anymore! We will show compassion and support anytime you need to talk.

However, peer conflict occasionally occurred when people raised their frustrations with a user's post, or in the responses of the post. Some people became frustrated when they felt the post included obvious signs of anxiety, which the user misunderstood for heart issues. Some people also felt that many younger people were misunderstanding anxiety symptoms with heart issues which became frustrating for them.

Some peers responded negatively towards 'bible preachers' and felt they should not be allowed further forum participation. Others disagreed occasionally with responders, leading to further conflict about the user's situation.

> 'Your worrying made me mad, absolute nonsense if you ignore the doctor's advice'.

5.5 | Relationships with the HCP

Peers frequently reported on their relationships and thoughts towards their HCPs. Some experienced disappointment after HCP consultations and decided to use online health forums to seek a second opinion. Others were pleased with their HCPs, trusting them and believing them to be experts. This relates mostly to the NPT constructs of cognitive participation (relationship work) as this relationship work extends beyond the peer engagement process and determines the link between the relationship with online health forums and HCP's. Reflexive monitoring (appraisal work) is also related to this theme because the interactions help inform the decision-making process, for example—whether the user will visit the HCP based on the information they received online (Table 2).

5.5.1 | Positive experiences with HCP's

People reported positive experiences with their HCPs after consultations. Some felt that they could trust the HCPs, since they were experts in their field. In addition, people were reassured when cardiologists had previously received good reviews, making them feel more comfortable and trusting. Moreover, it was discovered that some individuals felt nurses possessed a great ability to speak to them in a very relatable manner. This simplified their consultation experience enabling better understanding of the whole process.

> Above all, trust your Doctor, he is the expert.

> Cardiac wards usually have an educational nurse… they are good because you get the terms spoken with you and not at you with terminology that goes over our heads.

5.5.2 | Distrust with HCP's

Some responses expressed people's frustrations with their HCPs. Often, people felt dismissed and not listened to when visiting their HCP. Usually, this perception led them to online health forums for finding another HCP and seeking second opinions. Time issues were commonly reported: individuals said they often felt rushed during their consultations. Interestingly, there was the belief that some HCPs were only interested in receiving the fee after the appointment, hence recommending further visits for other tests to gain more money. Others felt their health issues were not taken seriously enough and lost trust with their HCP's knowledge.

> They have this obnoxious habit of not listening to patients, when we tell them things, they think they know better.

6 | DISCUSSION

This qualitative study aimed to examine the quality of diagnostic advice, and types of information being provided on heart failure online health forums. By interpreting and mapping the data against the NPT constructs, implications for support and research can be drawn.

The results show that most discussions on online health forums for heart failure focused on issues relating to diagnosis, experiences, information seeking, peer relations and relationships with HCPs. The findings are discussed, in addition to drawing comparisons and differences to previous literature. To our knowledge, this is the first paper to evaluate the quality of evidence provided on heart failure online health forums.

NPT helped to inform conceptualization of the themes of this study and structure the data. Relationship work (Cognitive participation) was a dominant feature of the data found in online health forums. This supports the suggestion that people are drawn to online health forums to build relationships and find similarities and comparisons in their health experiences with other peers. Online health forums can serve to legitimize patient perspectives and concerns. This peer-to-peer engagement process supports communication and relationship development. Reflexive monitoring was the next relatable construct as a lot of online health forum exchanges seemed to help inform decision-making about what to do next.

Our novel findings suggest that online health forums for heart failure could not be considered a reliable source of high-quality evidence-based information on diagnosis of heart failure, with only 11% of the responses including wholly or partial evidence, and 10% ($n = 29$) of responses being non-evidence based and potentially dangerous. The lack of information about peers, such as demographic data, made it difficult to know who an individual was engaging with. However, our findings suggest that gaining a diagnosis or having symptoms is only part of the reason people use such forums, and that people access such forums to gain support and have their concerns legitimized (cognitive participation work). The forums provide a community of support and experiential connectivity, which appears to be the key benefits of online health forums for those with heart failure.

Several factors identified, resonated with previous online health forum studies. Online health forums clearly provide and signpost helpful and supportive information to users (Cole et al., 2016; Mamykina et al., 2015; Sarrazin et al., 2014). Online health forums shared more than just diagnostic responses. They provided an opportunity to connect with peers around the world, to share experiences, and to build a supportive community which has been noted previously (Jeong et al., 2018; Lu et al., 2013; Sudau et al., 2014; Willis, 2014). Our findings suggest that for most people, the internet is used to complement, rather than replace offline sources, which is consistent with other research (Farnood et al., 2020; Tan & Goonawardene, 2017). Several concerns such as the potential for misinformation and conflict between peers, have been discussed in previous literature (Plinsinga et al., 2019). Furthermore, the anonymity of online health forums can introduce the increased likelihood of receiving hostile comments and misinterpretation due to the constraints of non-verbal communication (Coulson et al., 2007; Plinsinga et al., 2019).

Interestingly, responders rarely signposted users to consult nurses; rather they usually suggested visiting the doctor, general practitioner or cardiologist. Traditionally, primary HCPs were general practitioners. However, the nursing profession is expanding, and nurses are taking on more advanced and extended roles. Advanced nurse practitioners and primary care nurses are becoming more common, and this will continue to increase with time. It is expected for patients to increasingly refer to nurses on online health forums as the profession grows (McParland et al., 2020; McParland et al., 2019; Rea et al., 2020; Wilson et al., 2020). High quality online health forums that have been assessed, should be recommended to nurses and HCP's to potentially offer as a resource to patients.

Previous literature has suggested that HCPs should improve their awareness about online health information and communities, so they have greater knowledge of the types of informal social support networks patients are engaging in (Tan & Goonawardene, 2017). Future research should explore nurses' perceptions of patient/public online health information seeking. There is a lack of research including the nursing perspective and as the nursing profession expands and more roles continue to develop such as the advanced nurse practitioner, it is essential to develop an understanding of the impact of such online health forums on relationships between patients and nurses.

Additionally, further exploration on the use of moderators on online health forums to determine the key benefits in comparison to those not moderated, would be useful. Furthermore, as nurses are the largest group of healthcare providers worldwide (WHO, 2017), it is important for nurses and other HCP's to be made aware of the risk of patient's accessing incorrect and potentially harmful information as it will allow them to have a better understanding of patient knowledge gaps and to better address them. Technology and the nursing profession will continue to grow and there will be more contact between internet-informed patients and primary care nurses.

Therefore, it is important to understand the impact of this on the relationship between nurses and patients.

6.1 | Limitations

The approach to data collection assembled a diverse range of views from online health forums where individuals felt free to comment and engage in discussions unbounded by the formal constraints of the research environment, and with the protection of anonymity. This meant that the study could be based on an analysis of honest, publicly offered guidance, views, perceptions, and interactions concerning different heart failure conditions and scenarios. Another advantage of this method is its resource effectiveness and the fact that it facilitates access to large quantities of data in a relatively short amount of time.

However, as the discussion forum respondents remained anonymous; it was impossible to obtain complete information in respect of the demographic characteristics of the sample. The scale of the study was limited to online health forums discussing heart failure. Online health forums for different conditions could have yielded different results. However, while the characteristics of the sample inevitably remain ambiguous, the ability of this method to harvest spontaneous views is indisputable.

The posts analysed were anonymous, carrying few details about the user. Therefore, these yielded insufficient socio-demographic data, and the sample may not be entirely representative.

Although users were international and the online health forums were geographically based in the UK and US, for the purpose of the study and diagnostic level of responses, the NICE and SIGN guidelines were deemed appropriate to be used in terms of similarity to the American Heart Association guidelines (AHA, 2017). Careful consideration was taken prior to the study when analysing these guidelines, and during the analysis process.

7 | CONCLUSION

The ubiquitous nature of online health forums and peer to peer communication, and the continued expansion of online resources suggest the use of such resources is likely to gain increasing importance for HCPs. Online health forums allow peers to connect globally. They generate content which enables individuals to share their own experiences in the confines of the forum (Jeong et al., 2018; Lu et al., 2013; Sudau et al., 2014; Willis, 2014). However, online forums also represent an opportunity to provide misinformation and 10% ($n = 29$) of the information provided was unsafe and not evidence based. Nonetheless, such forums provide support, addressing issues of isolation and ensure users feel they are not alone (Cole et al., 2016; Mamykina et al., 2015; Sarrazin et al., 2014). Despite the growing use of online health forums, very little research makes use of this low-cost resource for identifying people's health interests to guide person orientated research, nor are we using this information to help us better understand patient support needs to underpin a more person-centred healthcare delivery. HCPs and health care systems should use learning from such forums to identify service gaps and care deficiencies to optimize care delivery. Online health forums may provide increasing benefit through the addition of a moderator.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

PEER REVIEW

The peer review history for this article is available at https://publons.com/publon/10.1111/jan.15009.

ORCID

Annabel Farnood https://orcid.org/0000-0001-5648-4495

REFERENCES

AHA. (2017). *Diagnosing heart failure*. Retrieved from https://www.heart.org/en/health-topics/heart-failure/diagnosing-heart-failure

Apps, T., & Phelan, A. (2018). Working together to achieve better outcomes for patients with heart failure. *Primary Health Care*, *28*(3), 35–41. https://doi.org/10.7748/phc.2018.e1348

BHF. (2020). *Information & support*. Retrieved from https://www.bhf.org.uk/informationsupport

Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57–71). American Psychological Association.

Brennan, E. J. (2018). Chronic heart failure nursing: Integrated multidisciplinary care. *British Journal of Nursing*, *27*(12), 681–688. https://doi.org/10.12968/bjon.2018.27.12.681

Browne, S., Macdonald, S., May, C. R., Macleod, U., & Mair, F. S. (2014). Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLoS One*, *9*(3), e93288. https://doi.org/10.1371/journal.pone.0093288

Chen, A. T. (2012). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counseling*, *87*(2), 250–257. https://doi.org/10.1016/j.pec.2011.08.017

Chew, H. S. J., Sim, K. L. D., Cao, X. I., & Chair, S. Y. (2019). Motivation, challenges and self-regulation in heart failure self-care: A theory-driven qualitative study. *International Journal of Behavioral Medicine*, *26*(5), 474–485. https://doi.org/10.1007/s12529-019-09798-z

Cohan, A., Young, S., Yates, A., & Goharian, N. (2017). Triaging content severity in online mental health forums. *Journal of the Association for Information Science and Technology*, *68*(11), 2675–2689. https://doi.org/10.1002/asi.23865

Cole, J., Watkins, C., & Kleine, D. (2016). Health advice from internet discussion forums: How bad is dangerous? *Journal of Medical Internet Research*, *18*(1), e4. https://doi.org/10.2196/jmir.5051

Coulson, N. S., Buchanan, H., & Aubeeluck, A. (2007). Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group. *Patient Education and Counseling*, *68*(2), 173–178. https://doi.org/10.1016/j.pec.2007.06.002

Cowie, M. R. (2017). The heart failure epidemic: A UK perspective. *Echo Research and Practice*, 4(1), R15–R20.

Dang, D., & Dearholt, S. L. (2017). *Johns Hopkins nursing evidence-based practice: Model and guidelines*. Sigma Theta Tau.

Daraz, L., Morrow, A. S., Ponce, O. J., Beuschel, B., Farah, M. H., Katabi, A., Alsawas, M., Majzoub, A. M., Benkhadra, R., Seisa, M. O., Ding, J. (F.), Prokop, L., & Murad, M. H. (2019). Can patients trust online health information? A meta-narrative systematic review addressing the quality of health information on the internet. *Journal of General Internal Medicine*, *34*(9), 1884–1891. https://doi.org/10.1007/s11606-019-05109-0

De Simoni, A., Shanks, A., Balasooriya-Smeekens, C., & Mant, J. (2016). Stroke survivors and their families receive information and support on an individual basis from an online forum: Descriptive analysis of a population of 2348 patients and qualitative study of a sample of participants. *British Medical Journal Open*, *6*(4), e010501. https://doi.org/10.1136/bmjopen-2015-010501

Escobar, C., Varela, L., Palacios, B., Capel, M., Sicras, A., Sicras, A., Hormigo, A., Alcázar, R., Manito, N., & Botana, M. (2020). Costs and healthcare utilisation of patients with heart failure in Spain. *BMC Health Services Research*, *20*(1), 1–11. https://doi.org/10.1186/s12913-020-05828-9

Farnood, A., Johnston, B., & Mair, F. S. (2020). A mixed methods systematic review of the effects of patient online self-diagnosing in the 'smart-phone society'on the healthcare professional-patient relationship and medical authority. *BMC Medical Informatics and Decision Making*, *20*(1), 1–14. https://doi.org/10.1186/s12911-020-01243-6

Gallacher, K., May, C. R., Montori, V. M., & Mair, F. S. (2011). Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *The Annals of Family Medicine*, *9*(3), 235–243. https://doi.org/10.1370/afm.1249

Gallacher, K., Morrison, D., Jani, B., Macdonald, S., May, C. R., Montori, V. M., Erwin, P. J., Batty, G. D., Eton, D. T., Langhorne, P., & Mair, F. S. (2013). Uncovering treatment burden as a key concept for stroke care: A systematic review of qualitative research. *PLoS Medicine*, *10*(6), e1001473. https://doi.org/10.1371/journal.pmed.1001473

Jeong, J.-S., Kim, Y., & Chon, M.-G. (2018). Who is caring for the caregiver? The role of cybercoping for dementia caregivers. *Health Communication*, *33*(1), 5–13. https://doi.org/10.1080/10410236.2016.1242030

Kummervold, P. E., Gammon, D., Bergvik, S., Johnsen, J.-A.- K., Hasvold, T., & Rosenvinge, J. H. (2002). Social support in a wired world: Use of online mental health forums in Norway. *Nordic Journal of Psychiatry*, *56*(1), 59–65. https://doi.org/10.1080/08039480252803945

Lee, K., Hoti, K., Hughes, J. D., & Emmerton, L. M. (2015). Consumer use of "Dr Google": A survey on health information-seeking behaviors and navigational needs. *Journal of Medical Internet Research*, *17*(12), e288. https://doi.org/10.2196/jmir.4345

Lin, T.-C., Hsu, J.- S.-C., Cheng, H.-L., & Chiu, C.-M. (2015). Exploring the relationship between receiving and offering online social support: A dual social support model. *Information & Management*, *52*(3), 371–383. https://doi.org/10.1016/j.im.2015.01.003

Lindsay, S., Smith, S., Bellaby, P., & Baker, R. (2009). The health impact of an online heart disease support group: A comparison of moderated versus unmoderated support. *Health Education Research*, *24*(4), 646–654. https://doi.org/10.1093/her/cyp001

Liu, X., Liu, J., & Chen, H. (2014). Identifying adverse drug events from health social media: A case study on heart disease discussion forums. Paper presented at the International conference on smart health.

Lu, X., Zhang, R., Wu, W., Shang, X., & Liu, M. (2018). Relationship between internet health information and patient compliance based on trust: Empirical study. *Journal of Medical Internet Research*, *20*(8), e9364. https://doi.org/10.2196/jmir.9364

Lu, Y., Zhang, P., Liu, J., Li, J., & Deng, S. (2013). Health-related hot topic detection in online communities using text clustering. *PLoS One*, *8*(2). https://doi.org/10.1371/journal.pone.0056221

Mamykina, L., Nakikj, D., & Elhadad, N. (2015). Collective sensemaking in online health forums. Paper presented at the Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems.

May, C. R., Cummings, A., Girling, M., Bracher, M., Mair, F. S., May, C. M., Murray, E., Myall, M., Rapley, T., & Finch, T. (2018). Using Normalization Process Theory in feasibility studies and process evaluations of complex healthcare interventions: A systematic review. *Implementation Science*, *13*(1), 80. https://doi.org/10.1186/s13012-018-0758-1

McParland, C. R., Cooper, M. A., & Johnston, B. (2019). Differential diagnosis decision support systems in primary and out-of-hours care: A qualitative analysis of the needs of key stakeholders in Scotland. *Journal of Primary Care & Community Health*, *10*, 2150132719829315. https://doi.org/10.1177/2150132719829315

McParland, C., Cooper, M., & Johnston, B. (2020). Exploring differential diagnosis decision support systems for trainee advanced practitioners in primary care. *Primary Health Care*, *30*(5). https://doi.org/10.7748/phc.2020.e1665

Nguyen, D. M., Olteanu, A., & Kıcıman, E. (2020). External information sharing on health forums: An exploration. Paper presented at the Proceedings of the International AAAI Conference on Web and Social Media

NICE. (2017). *Heart failure - chronic*. Retrieved from https://cks.nice.org.uk/topics/heart-failure-chronic/

NICE. (2018). *Chronic heart failure in adults: Diagnosis and management*. Retrieved from https://www.nice.org.uk/guidance/ng106

Pan, B., Hembrooke, H., Joachims, T., Lorigo, L., Gay, G., & Granka, L. (2007). In Google we trust: Users' decisions on rank, position, and relevance. *Journal of computer-mediated Communication*, *12*(3), 801–823. https://doi.org/10.1111/j.1083-6101.2007.00351.x

Plinsinga, M. L., Besomi, M., Maclachlan, L., Melo, L., Robbins, S., Lawford, B. J., Teo, P. L., Mills, K., Setchell, J., Egerton, T., Eyles, J., Hall, L., Mellor, R., Hunter, D. J., Hodges, P., Vicenzino, B., & Bennell, K. (2019). Exploring the characteristics and preferences for online support groups: Mixed method study. *Journal of Medical Internet Research*, *21*(12), e15987. https://doi.org/10.2196/15987

Prescott, J., Hanley, T., & Ujhelyi, K. (2017). Peer communication in online mental health forums for young people: Directional and nondirectional support. *JMIR Mental Health*, *4*(3), e29. https://doi.org/10.2196/mental.6921

Pruksachatkun, Y., Pendse, S. R., & Sharma, A. (2019). Moments of change: Analyzing peer-based cognitive support in online mental health forums. Paper presented at the Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.

Rea, T., Esposito, M. R., Guillari, A., Simeone, S., Gargiulo, G., Continisio, G. I., & Serra, N. (2020). Nurses in Public Health: A profession in continuous evolution. *Epidemiology, Biostatistics and Public Health*, *17*(1). https://doi.org/10.2427/13229

Robertson, N., & Harrison, P. (2009). What's wrong with me? Concerns about online medical self-diagnosis. Paper presented at the ANZMAC 2009: Sustainable management and marketing conference.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23*(4), 334–340. https://doi.org/10.1002/1098-240X(200008)23:4<334:AID-NUR9>3.0.CO;2-G

Sarrazin, M. S. V., Cram, P., Mazur, A., Ward, M., & Reisinger, H. S. (2014). Patient perspectives of dabigatran: Analysis of online discussion forums. *The Patient-Patient-Centered Outcomes Research*, *7*(1), 47–54. https://doi.org/10.1007/s40271-013-0027-y

SIGN. (2016). *Management of chronic heart failure*. Retrieved from http://www.sign.ac.uk

Sudau, F., Friede, T., Grabowski, J., Koschack, J., Makedonski, P., & Himmel, W. (2014). Sources of information and behavioral patterns in online health forums: Observational study. *Journal of Medical Internet Research*, *16*(1), e10.

Tan, S.-S.-L., & Goonawardene, N. (2017). Internet health information seeking and the patient-physician relationship: A systematic