Exploring pitfalls of online consumer health information use and potential preventive strategies

Reem El Sherif, MBChB
Department of Family Medicine
McGill University, Montreal
June, 2016

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master's of Science in Family Medicine

© Reem El Sherif, 2016

Table of Contents

List of Figures and Tables

Abstract

Background

There has been an exponential increase in the general population's usage of the Internet, and of information accessibility; the current demand for online consumer health information (OCHI) is unprecedented. In North America, more than 70% of adults have used the internet regularly to search for information in 2014, particularly OCHI.

There are multiple studies on Internet access and usage, quality of information, and information needs. However, there is a limited number of studies that examine information use and subsequent outcomes. Only a few studied negative outcomes (pitfalls) associated with using OCHI, and none looked at preventing them. A recent systematic literature review, in which I participated, identified three main negative outcomes reported by consumers and physicians: (a) increased worries and anxiety, (b) deterioration of the patient-physician relationship, and (c) overuse or misuse of health care services. This review was based on a conceptual framework of OCHI interactions and outcomes, and included studies in community-based primary health care setting (hereafter primary care), which involves primary health care topics and services, consumers (including patients) and multiple types of professionals.

Building on the results of this review, my purpose in this investigation was to describe negative outcomes associated with OCHI use in primary care setting, and identify potential prevention strategies from consumers', health practitioners' and health librarians' perspectives.

Methodology and methods

I conducted a two-stage descriptive qualitative study. In the first stage, I recruited, through a social media survey, a purposeful sample of 19 key informants (OCHI users) who had experienced negative outcomes associated with OCHI. I conducted semi-structured interviews with them to understand their perspectives, and analysed transcribed verbatim thematically using a deductive and inductive approach to identify types of negative outcomes. The results also informed the creation of vignettes that were used in the next stage. In the second stage, I interviewed a convenient sample of 10 key informants: seven health practitioners (three family physicians, two nurses, and two pharmacists), and three health librarians. With the support of the vignettes (stimulation of reflection and memory), I asked participants to elaborate on (a) their

experience with patients who have used OCHI and experienced negative outcomes, and (b) what strategies they suggest to prevent these outcomes. Similar to stage 1 and building on stage 1 results, I transcribed interviews (verbatim), and analysed them thematically using a deductive and inductive approach to describe types of negative outcomes and identify potential preventive strategies.

Results

Themes and subthemes related to types of OCHI, motivations for searching OCHI, use of OCHI, and positive outcomes associated with the use of OCHI were identified from both stages and described. This evidence helped me properly identify and interpret the negative consumer outcomes reported in both stages of this study. I therefore found that negative outcomes of OCHI may occur at three levels: internal (such as increased worrying), interpersonal (such as a tension in the patient-physician relationship), and service-related (such as postponing a clinical encounter). Participants also proposed three types of strategies to prevent the occurrence of these negative outcomes, namely: providing consumers with reliable OCHI, educating consumers on how to assess OCHI websites, and helping consumers present and discuss the OCHI they find with a health professional in their social network or a librarian for instance.

Discussion and conclusion

Unlike other studies, I examined negative outcomes associated with using OCHI from four complementary perspectives: previous studies', OCHI consumers', primary care practitioners' and health librarians' perspectives. I conceptualized the results using a comprehensive and meaningful new construct: OCHI use-related tension. This construct has three dimensions (three inter-dependant levels): internal, interpersonal, and service-related tensions. This construct enriches our conceptual framework of OCHI interactions and outcomes. Future research can focus on the implementation and effectiveness of the proposed strategies, which might contribute to prevent and decrease these internal, interpersonal, and service-related tensions.

Résumé

Contexte

L'utilisation de l'internet par la population et l'accessibilité aux informations croissent de manière exponentielle. Il existe actuellement une demande sans précédent d'informations en ligne sur la santé pour les consommateurs (*online consumer health information*) qui sont appelées Information de l'internet-santé (IIS). En Amérique du Nord, en 2014, plus de 70% des adultes ont utilisé internet pour trouver des informations, notamment des IIS.

Il existe de multiples études sur l'accès à l'internet, la qualité de l'information ou encore les besoins de la population en termes d'informations. Cependant, seul un petit nombre d'études examine l'utilisation des IIS et leurs effets. Rares sont celles qui étudient les effets négatifs de l'utilisation des IIS, et aucune n'étudie la prévention de ces effets. Une revue de littérature systématique récente, à laquelle j'ai participée, a identifié trois effets négatifs principaux rapportés par des consommateurs et des médecins : (a) une augmentation des inquiétudes et de l'anxiété, (b) une détérioration de la relation patient-médecin, et (c) une utilisation excessive ou inappropriée des services de soins de santé. Cette revue était fondée sur un cadre conceptuel des interactions et des effets des IIS, et incluait des études portant sur les soins de santé de première ligne qui sont offerts dans la communité (appelés ci-après les soins primaires). Ces études portaient sur des sujets et des services de soins primaires, et sur les consommateurs (incluant les patients) et les multiples types de professionnels qui travaillent en soins primaires.

Fondée sur les résultats de cette revue de littérature, mon étude visait à décrire les effets négatifs associés à l'utilisation des IIS en soins primaires, et identifier les potentielles stratégies de prévention du point de vue combiné des consommateurs, des bibliothécaires spécialisés en santé et des praticiens en soins primaires.

Méthodologie et méthodes

J'ai effectué une étude qualitative descriptive en deux étapes. Lors de la première étape, j'ai recruté un échantillon raisonné de 19 informateurs clés (utilisateurs d'IIS) à travers une enquête dans les médias sociaux. Tous mes informateurs ont fait l'expérience d'effets directs négatifs des

IIS. J'ai effectué une entrevue semi-structurée avec chacun d'entre eux pour comprendre leurs perspectives et j'ai retranscrit les entrevues mot-à-mot (verbatim). J'ai ensuite analysé ces entrevues en utilisant une approche déductive et inductive afin d'identifier les différents types d'effets négatifs. Les résultats des entrevues ont permis la création de vignettes, que j'ai utilisées dans l'étape suivante. Lors de la deuxième étape, j'ai recruté un échantillon de convenance de 10 informateurs clés : sept praticiens (trois médecins de famille, deux infirmières et deux pharmaciens) et trois bibliothécaires spécialisés en santé. Avec l'aide des vignettes (stimulation des réflexions et de la mémoire), j'ai demandé aux participants de décrire en détail (a) leur expérience avec des patients qui ont soufferts d'effets négatifs à la suite de l'utilisation d'IIS, et (b) les stratégies qu'ils utilisent afin de prévenir ces effets. Comme dans la première étape, j'ai transcrit les entrevues (verbatim) et je les ai analysées de manière thématique (approche déductive et inductive) pour décrire les différents types d'effets négatifs et identifier des stratégies de prévention potentielles.

Résultats

Les thèmes et sous-thèmes liés aux types d'IIS, aux raisons pour chercher des IIS, à l'utilisation des IIS et aux effets positifs associés à cette dernière, ont été mis en évidence au cours des deux étapes de ma recherche, et décrits. Ces évidences m'ont permis d'identifier précisément et d'interpréter les effets négatifs des IIS au cours des deux étapes. J'ai trouvé que ces effets négatifs peuvent survenir à trois niveaux : en interne (par ex., plus de soucis), au niveau interpersonnel (par ex., une relation patient-médecin plus tendue) et en lien avec les services de santé (par ex., remise d'un examen clinique à plus tard). Les participants ont également proposé trois types de stratégies pour prévenir ces effets négatifs : la transmission d'IIS fiables aux consommateurs, l'éducation des consommateurs sur les moyens disponibles pour évaluer les IIS, et l'aide offerte aux consommateurs pour présenter et discuter les IIS avec un professionnel de la santé au sein de leur réseau social ou une bibliothécaire par exemple.

Discussion et conclusion

Contrairement aux autres recherches, j'ai examiné les effets négatifs associés à l'utilisation des IIS selon quatre perspectives complémentaires qui sont celles des études antérieures, des consommateurs, des praticiens des soins primaires et des bibliothécaires spécialisés en santé. J'ai conceptualisé les résultats de mon étude avec un construit global : les tensions de l'utilisation des IIS. Ce construit a trois dimensions (trois niveaux interdépendants de tension : interne, interpersonnel et lié aux services de santé). Ce construit enrichit notre encadrement conceptuel des interactions et des effets des IIS. Dans le futur, les recherches pourront porter sur l'implantation et l'efficacité des stratégies de prévention proposées qui peuvent contribuer à prévenir ou apaiser ces tensions internes, interpersonnelles et liées aux services.

Acknowledgements

It is with great pleasure that I acknowledge the support and assistance of many individuals, without whom this thesis would not have been possible.

First and foremost, I would like to begin by expressing my gratitude to my supervisor, Dr. Pierre Pluye. Your guidance and support since I started the program have been invaluable. You always led by example, always encouraged me to learn new skills, to collaborate on different projects, and more importantly, to be a diligent and thorough researcher. You will remain my role model and my mentor, and I will always be grateful for your supervisorship.

I would like to thank my co-supervisor Dr. Charo Rodriguez, who for the past two years patiently and tirelessly guided me to build my skills in qualitative research, a field I had no experience with before her class. Her contribution to this thesis is evident in every page, and I could not imagine completing this project without her.

I am also very grateful for my thesis committee member, Dr. Christine Thoer, who very kindly contributed her expertise and time on this topic. Over the past two years she patiently reviewed my work many times and provided invaluable feedback, as well as excellent opportunities to present my work.

I could not have chosen better than the Department of Family Medicine at McGill University to pursue graduate studies. I am extremely thankful to Dr. Gillian Bartlett for her guidance since I started the program, she has been an excellent source of inspiration to all of us as a researcher, a teacher and a mentor. I would also like to thank Jamie DeMore who was a lifesaver many times, tirelessly answering my questions and helping with my applications to different awards and scholarships. And I would like to thank Dr. Isabelle Vedel and Dr. Jon Salsberg who were not only wonderful teachers while I was taking their classes, but also any time I had a question for them after that.

I am also very grateful for the multiple scholarships awarded to me by the Department of Family Medicine (entrance scholarships and a travel award). Moreover, I am grateful for the Faculty of Medicine Internal Studentship Award I received in my second year, as well as the CIHR Travel awards that allowed me to present my work in two separate conferences.

To my current and former FMED family who I could not have possibly survived the last two+ years without: Vera Granikov who has been my mentor and OCHI expert, and who taught me how to be a more organized and efficient researcher. Quan, Araceli, and Paula who have provided emotional support whenever I needed it and who let me bounce off all my ideas on them before directing me to the best solution. Justin, Stephanie, Christina, Nadia, Claire, Svetlana, Rachel, Kendra, Sherrie, Noura, Laura, Mathieu and Tamara for making the department my home away from home.

I am very grateful to the ITPCRG team whose weekly meetings provided a venue to share my ideas and improve upon them, and a valuable opportunity to learn from very experienced researchers. Thank you Dr. Roland Grad, Vinita, David, Michael, Diana, Maria, and Sarah.

Last but definitely not least, I am grateful for my parents: Nagwa and Emad. All I am and all I will ever be is because of your sacrifice, love and prayers, I can never thank you enough. Thank you Mohamed, Laila, Dima and Dana for being the best siblings an older sister can have. Thank you to my best friends who cheerfully put up with my complaining and my erratic availability and loved me anyway. And finally, thank you to my biggest cheerleader for the last few months, my Ahmed, who gave me something to look forward to every week while I worked.

I. Introduction

The purpose of this thesis was to advance knowledge on the complex human interaction with online consumer health information, and the potentially negative consequences of acquiring and using this information. Specifically, I wanted to explore what these negative outcomes could be from a consumer perspective based on their personal experience. Moreover, I wanted to uncover measures or strategies that could potentially prevent these negative outcomes from both consumers' and health practitioners' or health information providers' perspectives.

The Internet has become an essential part of our lives, particularly in the last decade, and its impact is widespread, geographically and across different fields. According to the International Telecommunication Union, a specialized agency of the United Nations, Internet penetration has increased almost seven-fold from 6.5 to 43% of the global population since 2000. In the last 2 years alone, the global Internet population grew nearly 20% – from 2.4 billion to 3.2 billion people. The proportion of households with Internet access at home increased from 18% in 2005 to 46% in 2015 [1]. Canada continues to be one of the most 'wired' countries in the world. According to the Canadian Internet Registration Authority (CIRA) nearly 87% of Canadian households were connected to the Internet in 2013, and Canada ranked 16th globally in terms of Internet penetration [2].

Furthermore, the amount of information on the Internet is staggering and increasing at an exponential rate annually. To put it in context, the Newstex team states that five exabytes (10^{18}) of content were created between the birth of the world and 2003. In 2013, five exabytes of content were created each day [3]. A large proportion of that content is undoubtedly in the field of medicine and health, especially online health information [4].

Online Consumer Health Information

Online consumer health information (henceforth OCHI) is the term generally used to refer to the information on health and diseases created for and directed to the general public [5]. There are generally two main categories of OCHI: expert systems and general information [6]. Expert or decision support systems use patient-specific data (for example, their lifestyle) to make personalized recommendations or programmed decision-making [6]. General information, on the other hand, is for non-programmed decision-making and is available in many formats: written, audio (for example, podcasts) and video. It is available in government health sites, professional organizations websites, health journals, online forums, and blogs among other sources. Moreover, consumers are also being passively exposed to OCHI 'posts' being shared by their social network through social media platforms such as Facebook [7].

American surveys of representative samples of the population have shown that the use of OCHI has increased dramatically since 2001, and the Internet was the most popular source of consumer health information while the use of other sources has decreased [8, 9]. In 2013, the Pew Research Center's Internet & American Life Project reported that 72% of Internet users reported they looked for OCHI within the past year and that 35% of US adults reported going online specifically to diagnose a condition for themselves or someone they knew [10]. The numbers in a Canadian context are similar; 67% of Canadians searched for medical or health-related information in 2012 [5, 11]. In Québec, 47% of the population aged 55 and older regularly uses the Internet, searching for information is their most frequent Internet activity after email, and the most frequent search topic is health information [12].

Consumers can use OCHI in many ways, most commonly in consultation with health practitioners, for engagement in healthcare, compliance with or modification of management plan, or support of relatives or friends with health conditions [13]. Increased access to OCHI is generally associated with increased consumer engagement in their own healthcare, increased empowerment of themselves and their families, and improved health outcomes [14-16].

The problem I examined in this thesis project stemmed from a systematic review looking at studies on online consumer health information use and outcomes in community-based primary health care setting[1] (hereafter primary care), which included 66 studies [17]. The majority of the outcomes reported in these studies are positive: reduced worries, increased satisfaction with health care services, increased involvement in decision-making, and improvement of health. However, 23 studies also mentioned a number of negative outcomes associated with using OCHI.

---

[1] Community-based primary health care setting involves: (a) primary health care topics (i.e., health promotion, disease prevention, early detection of a disease, and comorbidities), or (b) primary health care actors (i.e., individuals [self-care], community organizations, and clinicians such as community pharmacists and family physicians), or (c) primary health care services (i.e., first-contact care, care coordination, care over-time, and comprehensive care).

These studies described negative outcomes from either a physician or a patient perspective. One of the most well-known negative outcomes mentioned by both parties is increased anxiety, often referred to as ‘cyberchondria’. While this anxiety is often referred to as “excessive or overestimated”, it has nevertheless been noted as a real consequence of looking up and using OCHI [18, 19]. Another commonly reported outcome is deterioration in the patient-physician relationship, especially following sharing the retrieved information at a clinic encounter [20]. A third but infrequently reported outcome is the effect of using OCHI on the health care system, in terms of misuse or overuse of its resources; for example, longer, unnecessary encounters with the family physician [21].

That said, it is possible that there are other negative consequences associated with using OCHI we still do not know about. These consequences may be very common and inconsequential, or less common but quite serious. With the potential for exponential increase in OCHI use, these negative consequences are bound to also increase. It is, therefore, important to identify and understand these negative outcomes from the consumers’ viewpoint, and try to find ways to minimize, or prevent them.

In sum, the Internet has become a worldwide information pull and push technology the use of which has increased exponentially over the past decade. In the health sector, numerous studies and literature reviews on Internet access, quality of information, and patients’ information needs and seeking behaviour have been conducted. From this work, we know that Internet use generates important positive outcomes, but also a number of unintended negative consequences, still poorly reported and understood. Moreover, the majority of studies are set in an oncology or public health setting, and focus on specialized information or specific patient populations. However, in primary care, there are still only few studies about the use and outcomes of online consumer health information. This is problematic as not all results from a specialist setting or tertiary health care population are transferrable to a primary care setting.

Thesis Purpose

My purpose in this thesis was twofold: (1) to identify the pitfalls (i.e. negative outcomes) associated with OCHI use from consumers’, health practitioners’ and librarians’ viewpoints in primary care; (2) to report means to prevent these negative outcomes proposed by consumers, health practitioners and librarians.

II. Background

Over the course of my graduate studies, and while preparing for my research project, I have read numerous publications and reviews on OCHI which I will attempt to summarize here.

A. The Importance and Forms of Online Consumer Health Information

According to recent national surveys, more than six million citizens go online to look for health information in North America every day, specifically when they need advice or before they consult a physician. For example, the Pew Internet Report from 2012 indicated that approximately 80% of American adults have looked for one of 15 major health topics, and looking for OCHI is the third most popular online activity after email and online shopping [7]. These results are comparable to those of the Canadian population. According to a 2011 survey conducted in Quebec, 86% of Canadians have Internet access from any location, 73% use the Internet regularly, and the most frequently reported research subject was health information (63%) [22].

Consumers can access OCHI through an immense number of sources online; a Google search for 'health information' yields about 328,000,000 results. These websites range in diversity from reviewed scientific and institutional sources (e.g., Medline or the Heart and Stroke Foundation of Canada), to un-reviewed sources citing personal experiences (e.g., personal blogs or health forums), to un-reviewed non-reliable sources by quacks [23, 24]. Furthermore, social media now plays a large role in the dissemination and spread of OCHI, regardless of its reliability and accuracy[25].

Online consumer health information is most traditionally presented as facts and figures outlining the causes, presentation and management options of a disease. These sites are aimed to contribute to the consumer's basic knowledge of the condition and do not focus on the patient's personal experience with the illness [26]. Studies over the past decade have shown that people wish to understand their condition at a deeper level beyond scientific facts [26, 27].

An alternative to the traditional scientific websites are the online health communities or forums where consumers can interact with other people who provide personal experience information of their condition. This allows people to become better informed about their condition in the context of their own life, as well as receive emotional support [28, 29]. In fact, 34% of internet users, or 25% of adults, have read someone else's commentary or experience about health or medical issues in an online news group, website, or blog [25]. In addition to receiving advice and insights from people sharing their illness, consumers feel less lonely and isolated as a result of their condition [27]. The large number of such communities is a testament to their popularity among health consumers [30]. In fact, many healthcare organizations (Kaiser Permanente, John Hopkins, etc.) include access to online communities as part of their patient services [31].

B. Why and How Consumers Find and Assess Online Consumer Health Information

Information needs are the motivation for seeking information, and begin as a vague sense of unease in the individual's brain before they are recognized and articulated. Information needs are then transformed into a more understandable statement such as a formalized question which may then be compromised when information seeking actually occurs [32].

Many studies examine consumers' OCHI seeking behaviour and evaluation strategies [36-38]. There are multiple reasons to start an information seeking pathway such as curiosity, wanting to answer a personal question or someone else's health question, or to update current knowledge. Other reasons include deciding on whether or not to seek a health care service (such as a visit to the emergency room) or after a clinical encounter to complement the information provided by a health care provider [39, 40].

The majority of consumers tend to use a search engine, such as Google, where they enter an average of 4.2 keywords and examine, on average, the first four pages of results non-proportionately [36]. Consumers generally determine the reliability of a website source by the endorsement of a government agency or professional organization, and list ease of use, design and language as factors in assessing its credibility [37]. They spend an average of 10 seconds on a web page to decide if it is useful to them or not [26]. Furthermore, the majority of these consumers state they use multiple sources for verification of the information [38].

C. The Physician-Patient Relationship

The physician-patient encounter is “the pivotal starting point of any healthcare delivery”, and the physician-patient relationship has long been recognized as a keystone of healthcare [33]. It is the medium through which the medical problem is discussed, the diagnosis is reached, management plan is agreed upon, and support is provided [34]. For a lot of people, their health care providers are still considered the most accurate source of health information [35]. One of the most interesting observations over the last 30 years in Canadian health care system has been the change in the dynamics of the patient-physician relationship. Patients increasingly expect a discussion on the rationale and alternatives to any proposed management plan, rather than being spoon-fed health information by their physician [36]. The outcomes of this discussion may be an improvement of the physician-patient relationship or, as demonstrated in our systematic review, a deterioration of this relationship.

Throughout this thesis I will be referring to the patient-physician encounter as the clinical encounter since my study will involve health practitioners other than physicians.

III. Literature Review

While there is evidence available on OCHI use and its outcomes in primary care, few studies focus on the possible negative outcomes. There are also no reviews on the topic. Therefore, I conducted a mixed studies literature review before starting my empirical investigation. The question addressed in my review is: **"What are the negative outcomes associated with online consumer health information use from patients' and clinicians' viewpoints and lived experiences?"**

This review was conducted as a part of a larger CIHR-funded systematic mixed studies review with framework synthesis that examined all the outcomes associated with the use of OCHI in primary care [17, 37]. Details on the methods used are presented in Appendix I but a summary is presented below. The framework is described in full detail in the Methods section of this thesis.

Methods

1) Eligibility criteria were empirical research records that were in English or French, conducted in a primary care setting, were about online consumer health information geared towards the general public, and were about the use of online consumer health information.
2) Information sources were bibliographic databases (Medline, Embase, etc.), and grey literature sources (Google Scholar, ProQuest Dissertations and Theses, Theses Canada Portal).
3) Identification: The search strategy was established by three specialized librarians and adapted to different databases [38]. Records were imported into a specialised systematic reviews software (Distiller SR).
4) Selection was conducted by two independent reviewers (myself and another graduate student), and any conflict was resolved by discussion or arbitration.
5) Another reviewer and I extracted the results of the included studies using Nvivo 10, and used a convergent design with qualitative framework synthesis [39, 40]. We conducted a qualitative thematic analysis using an hybrid inductive-deductive approach (assigning study results to pre-defined themes, and creating new themes as needed) [41].

Results

The flow diagram is presented in Appendix I: 4322 records (title/abstract) and 161 full-text documents were screened; of those, 66 reported positive and negative outcomes; of those, 23 reported negative outcomes, and these are included in this review. A table summarizing the included studies is presented in Appendix I. The study participants were either consumers of the OCHI (patients, caregivers or the general public) or clinicians (family physicians or dentists). Nine of the included studies examined a specific intervention related to OCHI such as 'information prescriptions'[42] or 'information kiosks'[43]. The majority of the studies examined general online health information seeking behaviour and use. Based on my conceptual framework and the results reported in the selected studies, I describe below the major themes portraying the use and outcomes of relevant-OCHI. The themes concern the cognitive impact of the information, how the information is used, and the outcomes (positive and negative) of using the information.

Since the main goal of this review is to identify and describe the outcomes of using relevant OCHI, I will not weight the results of the synthesis using the number of included studies per type of outcome (vote counting). There are major conceptual reasons for this:

1. Every type of outcome or outcome-related idea mentioned in the literature is important to better understand these outcomes, whether it is mentioned in one study or in many studies.
2. Due to the heterogeneity of studies in terms of design, sample size, and reported outcomes, weighting becomes a complex task, and including numbers can be misleading (as it may indicate that equal weight is given to different studies).[44]

Therefore, while I report the number of studies that mention a particular idea, I do so only for a descriptive purpose since this information is not relevant in relation to the general purpose of my thesis.

A. Cognitive Impact of Online Consumer Health Information

After finding a relevant information webpage, and before a consumer can use it, the information is absorbed and understood; it has a cognitive impact [45]. One common impact is learning something new; in one study on 738 parents, 81% said the information they found improved their understanding of health care issues and they learned more about an illness or a specific symptom [46]. The Pew survey also reported that 81% of its respondents had indicated they had learned something new from the online information, and this proportion was higher (88%) in a third study [47, 48]. On the contrary, the information may remind its consumer of what they already knew or confirm what they are already doing.

Another important cognitive impact is reassurance; in one study, participants stated that finding the information online after a clinical encounter reassured them of the accuracy of their physician's recommendations [49]. In another study, Internet users surveyed also reported that the OCHI they found had a 'reassuring effect and reduced confusion with regard to their personal medical issues' [20]. This impact was also reported in a study where menopausal women who visited online community forums were reassured 'it was not only them' [50]. In a study on pregnant women, when the search topic was amniocentesis, participants stated that while they had been worried about the test, finding online information on the test made them 'more relaxed' [51].

The literature shows that not all cognitive impacts reported were positive. Occasionally, the sheer magnitude of the information available online may have a harmful effect on its consumers where they are more stressed the more they read [50]. In two separate studies on pregnant women, the information on the risks and problems of pregnancy promoted stress among some participants, especially when participants were already worried about a specific topic and encountered worse-case scenario situations [51, 52]. In a qualitative study on consumers 60 years and older, one consumer mentioned that reading the side effects of medications online 'scared her to death', a sentiment echoed by other participants in her focus group [53].

Consumers may find the information potentially harmful in some cases where the information source is not reliable or accurate. One example was pregnancy online forums where peer to peer advice given was based on personal experience or opinions and not rooted in facts. Following the advice on such sources without verification may lead to potentially harmful consequences [51].

In studies examining the perspective of practitioners, positive and negative cognitive impacts were also reported. One study reported that physicians perceived it as good that their patients who used the Internet had better knowledge of health issues and that this enabled them to have more elaborate discussions during the clinical encounter and to focus on more important points [54]. One study on MD's in Korea reported that 50% of physicians felt that OCHI improves people's understanding of medical conditions and treatments. This same study, however, reported that 85.4% of its participants disagreed with the statement that 'most patients are able to judge the relevance of Internet health information for their conditions'[55]. One study examining the perspective of family physicians reported that they attributed patient confusion on their 'limited ability to evaluate, personalize, and interpret abundant Internet health information [21]. In the literature this impact is mostly theoretical; participants acknowledge that inaccurate information could potentially have a negative cognitive impact [50].

B. Use of Online Consumer Health Information

Consumers can use the information they found in a variety of ways. One of the most commonly reported uses was in consultation with a health practitioner, where consumers discuss the information with their health care provider during a clinical encounter or use the information to formulate questions for their provider on their next clinical encounter [56]. In a study on the users of the Nova Scotia Health network, one in three reported that they had shared the information with their health care provider [57]. Similar US based studies reported that 34.9%, 36% and 53% of their respondents discussed the information with their provider [58-60]. Some studies reported lower proportions: 25% and 24% [46, 61]. Some studies reported strategies used by consumers to introduce the information during a clinical encounter, such as asking additional clarifying questions or challenging the physician's recommendation [54, 62]. One major barrier to bringing the information into the clinical encounter was fear of the physician's reaction to the information. Consumers who believed their provider would not be interested in discussing the information, would feel challenged or defensive, or would dismiss the information were less likely to bring the information into the encounter [51, 56].

Other examples of use reported by consumers in the literature is using the information to understand their health problem or to make health care related decisions. In one study on Internet users in the US, 67% of participants said that use of the Internet improved their understanding of health care issues, while fewer respondents said that the Internet affected more substantive decisions [63]. A study on Harlem adults found that 84% reported that information found online had improved their understanding of symptoms, conditions, or treatments in which they were interested [64]. Another study comparing Hispanics and non-Hispanics found that both groups reported that the information helped them better understand their condition and make decisions [65]. In a study on parents of school children, 81% of parents said that it improved their understanding of health care issues and they learned more about an illness or a specific symptom [46]. One study that examined the effects of providers prescribing 'information prescriptions' found that 35% of respondents said the information prescription improved their understanding of an illness or health problem [66]. Another study that compared participants who were given a MedlinePlus information prescription by their physician found that 74% compared to 40% agreed that the prescription helped improve their understanding of difficult concepts and procedures [67].

Some of the decisions consumers reported making using the information include deciding whether or not to make a clinical appointment with a health practitioner. In fact, one study found that 27% of participants confirmed that the information had replaced a clinical encounter with to their doctor [68]. In the Nova Scotia study, 24% of participants stated they used the information to decide to go to the doctor, and another 8% indicated that the information had helped them to decide not to go to the doctor [57]. In a study based in East Baltimore almost half (48%) said that OCHI affected their decision about whether to see a doctor [48]. Another example of decisions made is related to undergoing a diagnostic test, scheduling a screening test or adhering to a management option. A study that examined which decisions participants made using online information found that they were more likely to use the Internet for information related to elective surgery (36%) and prescription medication (32%) than cancer-screening tests (22%) [69]. The East Baltimore study reported that 59% of participants found that the information affected their decisions about health treatments or the way they help care for someone else [48].

In fact, another reported use of OCHI was to support someone else with a health concern. Five studies reported that participants shared the information with family members, friends or support groups [57, 65, 70-72]. In two other studies, the participants were caretakers and used the information to make health care decisions on behalf of other people [65, 73].

Consumers also used the information to be more certain of a management plan they are following or intend to follow, or to change the management plan altogether. Three studies reported that their participants used the information to confirm the treatment option they had been advised to follow or to be more confident in adhering to a prescribed drug [49, 72, 74]. Other studies mentioned a specific test (amniocentesis) or therapy option (hormone replacement therapy during menopause) that participants used the information to support their decision to undergo [26, 51]. Consumers also reported using the information to change the management of their condition. In five studies consumers reported making this change in the form of modifying their lifestyle or health behaviour based on the information found [20, 48, 75-77]. A less commonly reported use is using the information to challenge their provider's decision or to seek an alternative to the prescribed treatment [49]. One study reported that 11% of its respondents used online information to refuse or discontinue treatment recommended by their provider [78].

C. Outcomes Associated with the Use of Online Consumer Health Information

1. *Positive outcomes associated with use of online consumer health information*

Positive outcomes are commonly reported in studies on OCHI use. In line with other studies on information use, an informed patient is more likely to be involved in their healthcare decisions, and to demand and secure the most effective management; and thus, gain better clinical outcomes [79]. Informed patients are more likely to comply with their physician's management plan, gain satisfaction in their health care, and have their worries reduced. The information they seek may also lead to disease prevention or fewer disease complications [13, 74].

One of the most commonly reported positive outcomes is that consumers become more involved in their own healthcare, health or wellbeing as a result of finding and using OCHI. This can be in a number of ways; in one study on 738 parents, over half reported they had become more interested in health issues [46]. A study on 646 Harlem adults reported that the information they found online affected the way they eat (47%) or exercise (44%) [80]. A study describing the results of a survey circulated among 45,000 Internet users in Ohio, reported that OCHI is a significant component of people's self-health plan and results showed a positive relationship between health-related behavior modifications and OCHI [81]. Another study of 520 participants in East Baltimore reported that 67% said that OCHI improved the way they took care of their health [82]. In a report from a nationally representative survey of over 12,000 Americans, 48% said the information they found improved the way they took care of themselves [83].

Another way this increased involvement is showed when patients report feeling more prepared for a clinical encounter and more empowered to discuss their healthcare with their health practitioner. In one study on 851 adult patients, 76% felt more prepared for a consultation after accessing OCHI and 70% felt more able to participate in the decision-making process [61].

Another study of 89 patients at three osteopathic primary care clinics found that survey respondents reported asking more questions during clinical encounters (66%), following physician advice more closely (54%), and making self-directed dietary changes (54%) following the use of OCHI [84]. A mixed methods study reported that interviewees recognized that OCHI played a role in allowing them to become informed consumers, and thus, better able to share decisions with their health care provider [85]. Another qualitative study of 15 menopausal women found that after looking for and using OCHI they reported increased confidence when discussing their questions with their health care provider, as well as feeling more equipped and empowered during the clinical encounter [26].

As a result of using OCHI in discussion with their health care provider and becoming more involved in their health care, other common positive outcomes are improvement in the patient-physician relationship and increased satisfaction with health care service. In a mixed methods study of participants with chronic health conditions, it was reported that participants felt that their health care providers reacted positively to well-informed patients who were better able to ask informed questions and thus, save time and create a potentially desirable partnership between patient and care provider [72]. Findings from three studies show that OCHI seeking appeared to enhance the patient-provider relationship, through improved communication, as well as increased confidence in and compliance to the management plan [26, 67, 86].

Another beneficial outcome reported by OCHI seekers was being better able to manage their health problem after finding and using relevant OCHI. Findings from included studies show that study participants felt OCHI changed the way they felt about their health condition, felt better able to deal with their health problem, and in some situations, decided not to seek the help of a health care provider to deal with their health issue [48, 68, 80, 87]. Furthermore, other positive outcomes were health improvement and prevention of health problems. In five studies respondents stated that they believed their health had improved as a result of OCHI seeking and use, either through encouraging them to change their behaviour, by guiding their decision-making or supporting their physician’s management plan [55, 56, 68, 72, 88]. In one study on pregnant women, several interviewees stated that OCHI on nutrition they read during their pregnancy allowed them to modify their behaviour and prevented potential problems [51].

One of the most commonly reported motivations for OCHI seeking has been to reduce worries about a health issue, and one of the commonly reported outcomes has been reduced concern following the use of OCHI. In one study of 1,027 randomly selected Polish citizens, feelings of reassurance or relief were reported by 39% of respondents who used OCHI [89]. Another study reported that 122 of its respondents (52.1%) indicated that their anxiety about an illness or a health concern were reduced following OCHI use [71]. In another study of OCHI seekers, patients reported that health care provider's validation of their efforts were associated with reduced concern [62]. One study that examined the effectiveness of physicians providing health information prescriptions for their patients, reported that it reduced patient anxiety [90]. In two different studies that conducted focus groups and interviews with women who were OCHI seekers during their pregnancies concluded that reading about shared experiences similar to their own confirmed that what they were going through was 'normal' and helped reduce their anxiety [51, 52]. This was also echoed in a qualitative study of users of the NHS Direct website where participants reported that finding information on other peoples' experiences also reduced their concern [50].

Table 1 Summary of Positive Outcomes in Included Studies

	POSITIVE OUTCOMES							
	Increased care satisfaction	**Improved patient-clinician relationships**	**More involved in their**	**Better handle a problem**	**Prevention of a problem**	**Health improvement**	**Validation of knowledge**	**Less worried**
Ahmad (2006)		✓	✓					
Amirault (2005)								
Anderson (2004)		✓						
Ayers & Kronenfeld (2007)								
Baker et al (2003)								
Bansil et al (2006)								
Beck 2014		✓						
Berg 2011		✓		✓		✓		
Bianco 2013		✓	✓					
Bujnowska-Fedak et al 2007		✓						✓
Burton-Jeangros & Hammer (2013)		✓	✓					
Bylund et al (2007)	✓	✓					✓	✓
Caiata-Zufferey et al (2010)		✓					✓	
Campbell (2009)		✓	✓			✓		
Chung (2013)								

Coberly et al (2010)		✓	✓					✓
Cohall et al (2011)						✓		
Couper et al (2010)								
Diaz et al (2002)								
Dolan et al. 2004			✓					
Ettel et al (2012)		✓						
Gauld & Williams (2009)		✓						
Harbour 2007		✓	✓					✓
Hardey (2001)								
Hart et al (2004)		✓						
Hong (2008)								
Houston & Allison (2002)								
Iverson et al (2008)		✓	✓					
Kavathe 2009								
Kavathe (2010)			✓					
Kavlak et al (2012)								
Khechine et al (2008)								
Kim & Kim (2009)		✓				✓		
Kivits (2006)	✓	✓	✓					
Laflamme (2003)			✓	✓				
Lagan et al (2011)	✓		✓				✓	✓
Lev 2009		✓	✓		✓			✓
Liszka et al 2006						✓		
Liu et al. 2010								
Liu et al (2013)								
Macias & McMillan (2008)		✓	✓			✓		
Mayoh 2010	✓	✓	✓			✓		
Murray et al (2003)	✓	✓	✓	✓				
Neter & Esther; (2012)		✓						
Nicholas et al (2001)		✓		✓		✓		
Pena-Purcell (2008)		✓	✓					
Pifalo (1997)		✓						✓
PIP_Health_Report				✓		✓		
Porter & Edirippulige (2007)								
Powell et al (2011)		✓					✓	✓
Rice (2006)						✓		
Rideout (2001)								
Rogers & Mead (2004)	✓	✓	✓					
Shaikh et al (2008)								
Shinchuk et al (2010)								
Siegel et al (2006)		✓				✓		✓
Siliquini et al (2011)								
Sillence et al 2007		✓	✓				✓	
Sommerhalder et al 2009		✓	✓					
Ste et al (2012)								

Takahashi et al (2011)				✓				
Walsh et al (2012)								
Warner & Procaccino (2004)						✓		
Weaver et al 2009								
Ybarra & Suman (2008)	✓	✓						
Yoo & Robbins (2008)								

2. Negative outcomes associated with use of online consumer health information

Of 66 included studies, 23 reported negative outcomes (from a patients' viewpoint, or a physicians' viewpoint, or both; see Appendix I). The three main pitfalls identified were: worsening of the physician-patient relationship, increased anxiety, and misuse of health care services.

2.1. Increased worries

One of the most commonly reported reasons for seeking OCHI is to answer a personal health question or assuage a personal health concern. While the literature confirms that OCHI acquisition and use helps to reduce worries, an increasing number of studies show that it may also lead to increased worrying and health anxiety. Health anxiety is a phenomenon that ranges from intermittent worry to a pathological preoccupation with fears of illness that may meet criteria for a diagnosis of hypochondriasis [91]. This increased health anxiety as a result of OCHI seeking is so commonly reported that it has led to the coining of a new term: "cyberchondria" [19, 92]. As demonstrated by the studies in our review, this may be due to the sheer enormity of OCHI available, the presence of unreliable information sources, individual consumer characteristics that make them more vulnerable to worrying, or a combination of different factors.

Increased patient anxiety was reported in three included studies from the physicians' perspective. A study exploring physicians' point of view on patients using OCHI reported that physicians believed that it resulted in patient 'distress' which was perceived by the physician as increased worrying, anxiety, confusion or panic. They attributed this distress to their patients' limited ability to evaluate and interpret the information they found, and believed it made them 'sicker' [21]. In another study examining patient-physician interactions, practitioners reported observing that the Internet played a role in feeding the anxieties of patients with hypochondria [93]. A third study exploring the viewpoint of 493 physicians reported that 74.5% of participants believed OCHI made their patients over-concerned about their health [55]. A study on the implementation of an Information Prescription program reported that while some physicians who used the program believed it benefitted their patients in many ways and reduced their anxiety, an equal number of physicians believed the additional information could increase anxiety for some of their patients [67].

Furthermore, increased anxiety was also reported in studies that examined the consumer or patient perspective. In one study, 25% of participants who were randomly surveyed from the Polish population reported that finding OCHI increased their anxiety [89]. In another study where interviews were conducted with patients who searched for OCHI before or after a medical consultation, patients reported that they had stopped looking for health information online after experiencing past negative experiences with searching, specifically, becoming ‘very scared’. Their physicians had advised them to stop searching for health information online because they were not interpreting the information correctly, and thus, becoming increasingly more worried after reading it [49]. In a study on the perspectives of pregnant women who use the Internet to find health information, participants stated that they were aware of its limitations. The major limitation they had personally experienced was increased anxiety because the Internet made them unnecessarily aware of the many risks and problems that can occur during pregnancy [94].

Two studies revealed that there are individual characteristics in health information seekers that make them more likely to become more worried after finding relevant information. One study examined the relationship between health anxiety and health-related Internet usage in 255 university students. It reported that health anxiety correlated positively with the frequency of searching for OCHI, and that more time is spent online for health purposes overall in individuals with higher health anxiety [95]. Another study that examined how people used the Internet for different reasons through an online survey suggested that individuals with even moderate levels of anxiety seek higher amounts of OCHI [96].

Five other studies also reported anxiety and increased worrying as a consequence of OCHI use, either because the information was inaccurate, or because the consumer was misinterpreting the information or using it to make a detrimental self-diagnosis [50, 53, 71, 77, 97]. In three studies consumers reported that the sheer magnitude of health information available online overwhelmed them and tended to increase their anxiety, occasionally leading some people to abandon the Internet as a source of health information [51, 56, 93]. While there is a wide spectrum between a small increase in worries and a more severe form of cyberchondria, it is well established in the literature that this is a negative consequence of seeking and using OCHI.

2.2. Worsening of the physician-patient relationship

Our included studies explored the health care providers' perspective on their patients' use of OCHI, and what their experiences were with patients bringing the OCHI they found into the clinical encounter. One study conducted focus groups with 48 practicing family physicians to understand the effects of incorporating OCHI into routine medical consultations from their perspective [21]. In this study, physicians generally viewed OCHI as problematic when it was introduced in the consultation as it had the potential to generate patient misinformation which leads to confusion, distress and potentially harmful self-management. They felt that this therefore challenged their authority and added a new responsibility in their role as health care provider to interpret and clarify the information to their patients, which was seen as an unwelcome, time-consuming burden. In some cases this lead to some physicians 'firing' their patients, charging them for extra time, or referring those who they deemed more 'difficult' to another physician; all strategies that undermined the physician-patient relationship [21]. Another study with also examining physicians' perception of the effects of OCHI on the physician-patient relationship circulated a questionnaire to almost 500 physicians, 89% of whom had experience with patients using OCHI [55]. Overall they acknowledged that OCHI may enhance patients' knowledge about their health. However, around 60% perceived that it damaged the time efficiency of the clinical encounter, and 38% felt it damaged the physician-patient relationship, possibly because they felt that some patients lacked trust in their physicians' skills [55].

There were also many studies looking at this issue from the patients' perspective. One study included qualitative interviews and observations of patient-physician interactions with 47 patients, and explored how the use of OCHI is changing the relationship [35]. It was reported that some health practitioners would dismiss the OCHI acquired by the patient, instead exerting their medical authority over the patient [35]. In a study exploring the experiences of 50 pregnant women with OCHI, interviewees reported that their health care providers were dismissive of the information found online, claiming it was 'nonsense' and unreliable [51]. Other times, interviewees found that their health care provider's reaction was more defensive, that they were feeling threatened by the information being brought in and that their authority was being challenged. These negative reactions resulted in patients not discussing their acquired OCHI with their provider and, in some cases, changing health care providers altogether [51]. Another study that conducted focus groups of older OCHI consumers had similar findings; participants reported that their health care provider had a negative reaction to them bringing OCHI into the clinical encounter, in one case asking patients to stop making appointments if they will continue to self-diagnose using the Internet [53].

Four other studies that reported a negative change in the physician-patient relationship followed a similar pattern to the studies described above. Physicians' reactions to the OCHI ranged from dismissive to defensive to aggressive, which prompted patients to stop (searching for OCHI in rare cases) sharing the acquired OCHI with their physicians [65, 72, 74, 87]. Occasionally, patients were forced to change their health care provider either of their own accord because of increased tension or because they were referred elsewhere or 'fired' by their physician.

2.3. Misuse or overuse of health care services

The third negative outcome of OCHI use identified in our review is not consumer related, but in fact related to health care services. In a study examining the reactions of physicians to patients using OCHI, many physicians reported that encounters in which they were expected to interpret and discuss the acquired health information were a burden on their clinical responsibilities. These encounters were often described as time-consuming, problematic and difficult [21]. In another study that surveyed physicians on their point of view on OCHI, over half believed that it increased the cost of health care via inappropriate health service utilisation while around 60% reported that it damaged the time efficiency of the clinical encounter [55]. In another study on a nationally representative sample of American people, 39% of respondents agreed that OCHI could cause unnecessary encounters with a physician, while 37% believed that it caused patients to take up more of their physician's time [98]. A study comparing the use of OCHI by Hispanics and non-Hispanics found that the former were more likely to agree that seeking health information on the Internet promotes unnecessary visits to the doctor than the latter [65]. Another study that examined how people used the Internet for different reasons through an online survey reported that frequent online seekers also tend to make more medical appointments based on information found online [96].

Table 2 Summary of Negative Outcomes in Included Studies

STUDY (YEAR)	**STUDY DESIGN**	**VIEWPOINT**	**NEGATIVE OUTCOMES**		
			Deterioration of patient-physician relationship	**Increased worries and anxiety**	**Overuse or misuse of healthcare services**
Berg (2011)	Mixed methods	Consumers*	√		
Bujnowska-Fedak et al. (2007)	Quantitative descriptive	Consumers		√	
Chung (2013)	Quantitative descriptive	Consumers	√		
Eastin and Guinsler (2006)	Quantitative non-Randomized	Consumers		√	√
Kivits (2006)	Qualitative	Consumers	√		
Murray et al (2003)	Quantitative descriptive	Consumers	√		√
Pena-Purcell, (2008)	Quantitative non-Randomized	Consumers	√		√
Pifalo et al., (1997)	Quantitative non-Randomized	Consumers		√	
Powell et al. (2011)	Mixed methods	Consumers		√	
Singh and Brown (2014)	Quantitative non-randomized	Consumers		√	
Takahashi et al (2011)	Quantitative descriptive	Consumers		√	
Macias & McMillan (2008)	Qualitative	Consumers (older than 60 y/o)	√	√	
Bianco (2013)	Quantitative non-Randomized	Consumers (parents)	√		
Caiata-Zufferey et al (2010)	Qualitative	Consumers (patients)		√	
Hart et al (2004)	Qualitative	Consumers (patients)	√	√	
Iverson et al (2008)	Quantitative descriptive	Consumers (patients)	√	√	
Rogers & Mead (2004)	Qualitative	Consumers (patients)		√	
Burton-Jeangros & Hammer (2013)	Qualitative	Consumers (pregnant women)	√	√	
Lagan et al (2011)	Qualitative	Consumers (pregnant women)		√	
Lev (2009)	Qualitative	Consumers (pregnant women)	√	√	
Siegel et al (2006)	Quantitative descriptive and non-randomized	Consumers and physicians		√	
Ahmad et al. (2006)	Qualitative	Physicians		√	√
Kim and Kim, (2009)	Quantitative non-Randomized Study	Physicians	√	√	√

*Unless otherwise specified, participants were from the general population of consumers

Knowledge Gaps

Based on the literature review the following knowledge gaps were identified:

- We found 66 studies about OCHI-use and subsequent positive and negative outcomes in primary care. There are a number of studies in oncology and mental health, but their results are not necessarily transferable to primary care.
- We found no studies on OCHI in primary care that expanded on **negative outcomes** from the consumers' viewpoint. Twenty-three studies reported patients' and clinicians' viewpoints and experiences related to negative outcomes of OCHI use. These negative outcomes were reported briefly or incidentally in 20 studies; only three qualitative studies expanded on them, but focused on specific populations (two on pregnant women, one on patients with chronic diseases).
- Of these 23 studies, 20 were exclusively from the consumer viewpoint, two were from the clinicians' viewpoint, and only one examined the viewpoint of both. The only clinicians included in these studies were family physicians, no other health care provider perspective (such as that or nurses or pharmacists) was reported. Moreover, although they are information specialists, no studies examined the perspective of health librarians.
- **No studies** examined how these negative outcomes could be prevented or reduced.

Research Questions

Accordingly, my specific research questions are:

Question 1.

(a) What are primary care OCHI consumers' negative experiences of using OCHI?
(b) What strategies do they suggest using to avoid negative outcomes?

Question 2. What are health practitioners' and librarians' viewpoint about the strategies to potentially prevent consumers' negative outcomes when these consumers use OCHI?

IV. Conceptual Framework

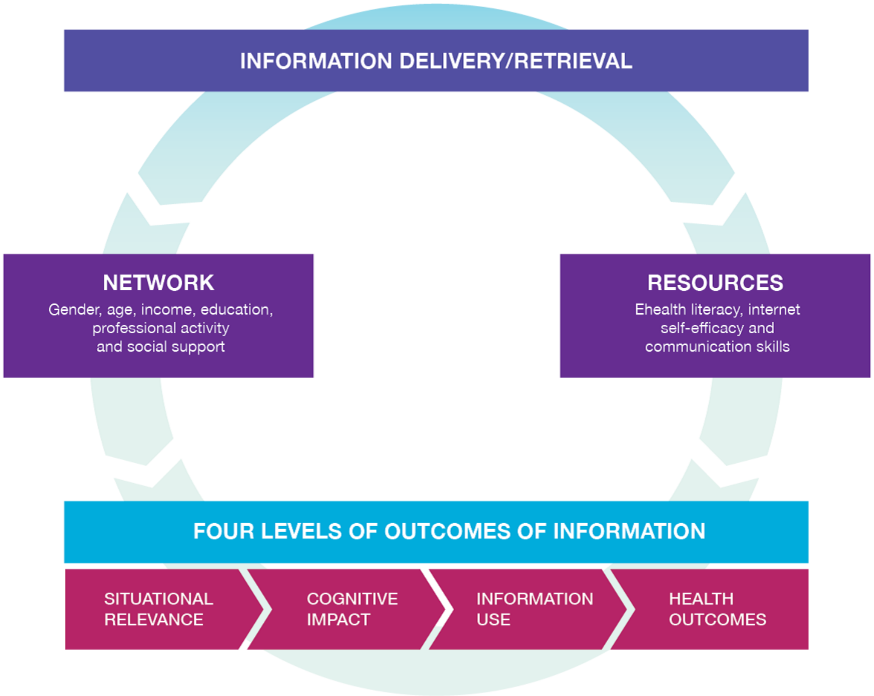


Figure 1. Conceptual Framework

This conceptual framework is derived from information studies [99], and includes four levels of outcomes of information delivery and retrieval [100, 101]: situational relevance, cognitive impact and use of information, and subsequent health/well-being outcomes. The levels reflect how information is valuable from the user viewpoint, and follow an iterative 3-stage process: people receive or retrieve information (Acquisition), understand and integrate it (Cognition), and possibly use it (Application). These levels are defined in relation to a specific information-seeking context: a particular information object is acquired, for example, a web page, in a specific situation, for example, a clinician–patient encounter.

- *Situational relevance* is when the search objective is met, and includes examples such as ‘answering a personal health question’.
- *Cognitive impact* where information is absorbed, understood, and integrated such as ‘better understanding of health or health care’.

- *Information use* is any way the information is used by the consumer such as 'in consultation with a health practitioner'.
- *Health outcomes* as a result of using this information such as 'reduction of worries.

Furthermore, in line with Savolainen (2002), our conceptual framework is patient-centred and contextual, i.e., includes "the social context, interaction and discourse through which the sharing of information occurs" [102]. First, we consider the patients as active interpreters (reflexive patients) of their own information in specific situations [103]. Second, we consider our context as *information-use in everyday life*, while information studies traditionally focus on working environments and workers, e.g., clinical settings and health practitioners [104]. Information theories successively defined the notion of context as (a) the social environment [105], (b) the community, culture, knowledge, and power system, and (c) a social environment temporarily created when people share information [106]. Similar to Courtright's literature review, we define the context using two key elements influencing information-use the patients' network and the patients' resources [107]:

- *Patients' network:* Gender, age, income, education, professional activity, cultural identity, immigration status, and language, determine a patient's network, and are factors of information-seeking and use.
- *Patients' resources* are patients' individual factors influencing their search for and use of online consumer health information such as information-seeking behaviour, health literacy, computer literacy, and communication skills.
    - Information-seeking behaviour: For example, information-seeking behaviour varies along a continuum from (a) inquisitive and autonomous people who look for any potentially relevant OCHI, to (b) people who selectively choose information, to (c) people who avoid information [108, 109].
    - Health literacy: the capacity to obtain and understand health information and services needed for appropriate decision-making [110]. A low level of health literacy is defined as a difficulty in acquiring, understanding, and applying health information by oneself [111].
    - Computer literacy: individuals who have higher computer literacy are more comfortable using this technology to seek health information and to then use this information in their health care decision-making [112].

    - Communication skills: it has been reported that good communication skills allows patients to have better communication with their health care providers, and is linked to better health outcomes [113].

While preparing for the study, I used this general framework as an overarching guide to develop my interview guides. I also used the levels of outcomes described by the framework to prepare my deductive codes during the thematic analysis of the interviews. I believe my work examining negative outcomes enriched areas of this framework, specifically related to ‘health outcomes’.

V. Methodology

Study Design

My research questions required documenting two different viewpoints: that of a consumer of online consumer health information who has experienced negative outcomes, and that of providers of health information having experience with these consumers (such as primary care health practitioners and health librarians). To this end, I conducted a two-stage descriptive qualitative study which allows researchers 'to obtain straight and largely unadorned answers to questions of special relevance to healthcare providers or policy makers' [114]. The participants of this project were consumers of OCHI, and primary care health practitioner and health librarians. The rationale for this two-stage design is that I used stage-1 results to inform stage-2 data collection. Methods and results are reported using the consolidated criteria for reporting qualitative studies (COREQ) [115].

Stage 1- Consumers (Objective 1, Questions 1(a) and 1(b))

A. Sampling

I used a purposive sampling strategy to find participants who had experienced negative outcomes after using online consumer health information for themselves. To that end, I created a short survey using SurveyMonkey that I used as a recruitment tool on different social media venues (Appendix II). Searching for maximum variation, this approach allowed me to find a broad range of potential cases from different populations, age groups and genders [116]. The survey collected the respondents' gender and age, explained what the purpose of the study was, and asked 4 questions:

- Have you ever used online health information in any of the following ways? (Check from a list of the five uses of online health information and a sixth option 'Other')
- Have you had any outcomes as a result of using this information? (Positive, negative or both)

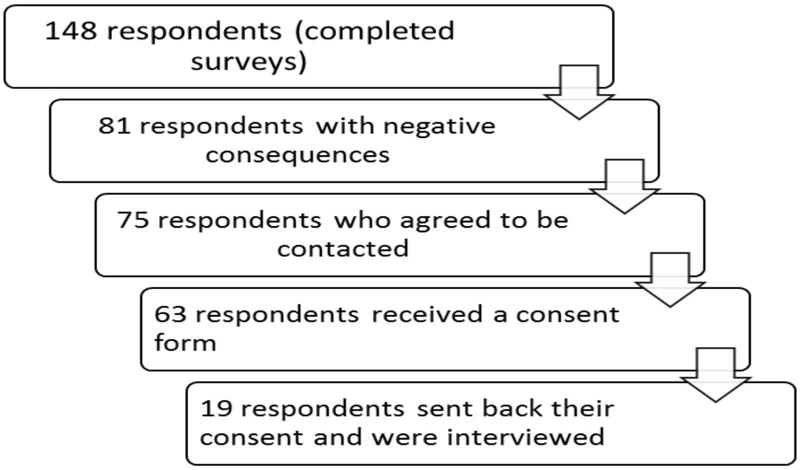
- Which of these outcomes have you experienced? (A list of outcomes derived from the literature that could be positive or negative)
- Would you be willing to be contacted for an interview to discuss this outcome? Please provide a contact number/email.

The first question about use was mainly a reflexive exercise that allowed the respondent to reflect on their understanding of the use of OCHI and to perhaps remind them of memorable incidents that had led to positive or negative consequences. The second question allowed the respondent to decide if that outcome was only positive, only negative or if they had experienced both. The response to this question determined their eligibility for the study as I was only interested in respondents who had experienced only negative consequences, or both positive and negative ones. The third question listed the outcomes derived from the literature review and could be either positive or negative, for example, one option was ‘increased or decreased worries’. The responses would serve as a reminder of their experiences and be further discussed during the interview stage with each respondent. The fourth question was to recruit willing participants from the eligible respondents.

Month	**Site**	**Number of responses**
July 2015	Facebook	13
September 2015	Email list	14
October 2015	LinkedIn & Facebook groups	121

I created the survey in July 2015, and ‘shared’ it on my Facebook timeline while limiting it to my contacts in Canada only. I received 13 responses (completed surveys), from which I contacted 3 key informants for pilot interviews that were not included in the analysis. I next circulated the survey via the McGill Family Medicine department in September 2015, and encouraged respondents to circulate it to their network, after which I received 14 responses. Finally, in October 2015, I shared the survey link on my LinkedIn profile and posted it on multiple Montreal based Facebook groups after receiving permission from their admins. I received a total of 121 responses after which I removed the post and started the data analysis.

I used this method to allow ‘maximum variation sampling’ of participants who have specifically experienced negative outcomes [117]. Key informants were purposefully selected to include a wide range of ‘dimensions’, in this case, negative outcomes.



In total, I received 148 responses (completed surveys), 81 in which respondents had indicated that they had experienced a negative consequence of using OCHI and, of those, 75 respondents who had agreed to be contacted and provided a method of contact. These respondents were emailed a consent form (Appendix III) by order of response (five a day) and asked to send back their statement of consent if they agreed to be interviewed. I then emailed them back to arrange a suitable time to schedule the interview, as well as a phone number to reach them at. I indeed interviewed 19 participants whose profiles respected the maximum variation sampling strategy considered.

B. Data collection

The data collection instrument was semi-structured phone interviews which, in addition to being a more convenient method because of participants’ geographical dispersion and their time constraints, had many methodological strengths [118]. While phone interviews are not a conventional method of data collection in qualitative research, many studies have found that they can provide data that is rich, vivid, detailed, and of high quality [119]. The interviews lasted between 10 and 20 minutes, which is shorter than the average interview length in qualitative in-person interviews. The literature shows, however, that 15-20 minute interviews are much more common in phone interviews with participants who may be too busy to schedule longer interviews [120]. Moreover, the pilot testing showed that the interview guide questions, their answers and any discussion on the topic would not last longer than 20 minutes.

Following a semi-structured interview format [121], questions were prepared in advance and the interview guide is presented in Appendix IV. A preliminary version of the guide was presented to a group of fellow researchers for feedback and pilot tested on two graduate students from the McGill Department of Family Medicine, and then modified to its final version. These two pilot tests were not included in the analysis. The final interview guide contained nine questions, while additional questions were asked to elaborate on the issues brought up by the interviewees.

After introducing the purpose of my study, the participants were asked general questions about online consumer health information, and the context and resources of their information seeking. They were asked if the information usually made sense to them (if it had a cognitive impact) and how they generally used the information they found (for example, to discuss with their physician or to make a decision). The participants were then asked to elaborate on their negative experience with OCHI use by telling their 'story', and what factors they believe may have led to these outcomes. They were also asked what they think could have been done to prevent these outcomes. Their anonymity was assured by use of pseudonyms and no personal information was included in the interview transcripts [122].

The interviews were recorded on my cell phone using an app called ‘Call Recorder’. The avi. format files were then downloaded and stored onto a flash usb drive that only I had access to and, consequently, deleted from my phone. Using a ‘foot pedal’ and a transcribing software (Express Scribe Transcription Software), I transcribed the interviews and also securely stored them. Transcribed interviews were imported into an Nvivo 11 project for qualitative data analysis. The interviews were conducted, transcribed and analyzed five at a time to ensure that I continued interviewing until saturation was reached [123].

C. Data Analysis

I used Nvivo 11 for helping me with the organization of qualitative data and thematic analysis. Using Nvivo 11, I imported the transcribed interviews after anonymizing their names in the transcripts and I performed a thematic analysis. I coded the transcripts from the interviews with consumers into themes identifying types of use and the type of outcome. A deductive-inductive analytical approach was adopted [41]. Fereday and Muir-Cochrane outline six stages of data coding and identification of themes: (1) developing the coding manual; (2) testing the reliability of codes; (3) summarizing data and identifying initial themes; (4) applying templates of codes and additional coding; (5) connecting the codes and identifying themes; (6) corroborating and legitimizing coded themes [41]. Each theme will refer to a “coherent and meaningful pattern in the data” relevant to the research question in that it directly answers it or provides a context [124].

Before I started coding, following the above steps, I used our conceptual framework and literature review to create a coding manual of the types of use and types of outcomes, both positive and negative. The types of use were one of the five types of use previously identified such as using the information in discussion with a health practitioner during a clinical encounter. The types of outcomes were also those identified in the literature review, such as feeling less worried about a health condition.

While coding, following an inductive approach, if a new type of use or outcome was identified in the transcript that did not fit into an existing code in the manual, I would create a new inductive code. For example, one interviewee described how using the information to self-manage led to delayed recovery from her health problem. Moreover, new codes were created for any preventative measures suggested by the interviewees at this stage. After completing all the coding, I then discussed my coding manual and coding results with my co-supervisors until a consensus was reached. The final coding manual is in Appendix V. The codes were then clustered into themes and corroborated with the coded data. It is important to note that, while considering recurrent issues, I adopted a rather inclusive approach and consider a “theme” any meaningful “pattern” that I could identify in the whole corpus of transcribed verbatim analyzed, even if this pattern was highlighted by one or very few participants.

I then performed a secondary analysis of the interview transcripts using a story telling technique [125]. This involved viewing the interview transcript through ‘multiple lenses’ and developing interpretive stories based on those views [126]. These stories, or vignettes, were created to represent each of the different types of negative outcomes uncovered in the literature review and the interviews, and to be used in the second stage of the project to introduce the topic to the health practitioners and health librarians. This analysis also led to the revision of the interview guide for the second stage of the project.

Stage 2- Primary Care Practitioners and Health Librarians (Objective 2, Question 2)

A. Sampling

The second stage was in line with my second objective to identify strategies to prevent or alleviate the potential negative outcomes of using OCHI. I therefore wanted to interview traditional health information providers who also have experience with consumers who use OCHI. To that end, the participants in this stage were both health practitioners and health librarians.

Practitioners were primary care health providers and included family physicians, registered nurses or nurse practitioners, and community or clinical pharmacists. These practitioners were selected because they are considered a primary source of health information for their patients. In fact, numerous studies show that many individuals still consider health practitioners to be the most trusted sources of information, especially to help them make sense of the online information they find [127, 128]. These practitioners also have experience with consumers (who may be their patients) who use OCHI, most commonly in discussion of the information during a clinical encounter. They, therefore, may have observed negative outcomes of using this information, and have insight into how these outcomes may have been prevented. They were also likely to have developed strategies to deal with OCHI in a clinical encounter in a manner that may prevent or alleviate these negative outcomes.

Health librarians were also essential participants in this stage due to their valuable experience dealing with OCHI and its consumers. As stated in the policy statement of the Medical Library Association and the Consumer and Patient Health Information Section ‘their knowledge of and skills in the identification, selection, organization, and dissemination of information, play an important role in both consumer health information services and patient education’ [129]. Due to their expertise on OCHI and its sources, these participants were considered key informants on the possible preventative measures that could be taken to prevent negative consumer outcomes [123]. They were also librarians that worked in a hospital setting and had experience dealing with patients as well as health practitioners seeking health information.

I conducted a purposeful sampling of these key informants in Montreal and Ottawa. Using personal contacts in the Department of Family Medicine and the School of Information Studies at McGill, the Herzl Family Medicine Clinic, the Jewish General Hospital, and the Canadian Pharmacists Association of Canada, my supervisor and I invited primary care practitioners and health librarians to participate by email. Potential participants were emailed an invitation letter from my supervisor explaining the project and the purpose of the interview, as well as the consent form (See Appendices II and III).

B. Data collection

The data collection tool in this stage were in-person semi-structured interviews that lasted between 30 and 60 minutes. Semi-structured in-depth interviews are the most widely used interviewing format for qualitative research, and while most questions are prepared ahead of time, interviewees are also given the freedom to express their views in their own terms [130]. After agreeing to participate in the study by email, a time and location for the interview were decided between myself and the participant. All the interviews were conducted at the practitioner's or librarian's office (either in a clinic or hospital).

After introducing the purpose of the study and describing the previous stage of interviews with consumers, as well as explaining the purpose of the second stage interviews, participants read and signed the consent form. At the beginning of the interview, to further illustrate the types of negative outcomes of OCHI, three of the vignettes created from the first stage of interviews were presented to the interviewees. This presented them with an opportunity to reflect on the negative outcomes resulting from OCHI use and refreshed their memories of their own experiences. They were then asked to give their opinion on the situations described in the vignettes, as well as elaborate on their own experience with consumers or patients using OCHI.

Following a semi-structured interview format [121], the interview guide was prepared in advance and is presented in Appendix IV. A preliminary version of the guide was presented to a group of fellow researchers for feedback and pilot tested with a family physician and health librarian from the McGill Department of Family Medicine, and then modified to its final version. These two pilot tests were not included in the analysis. The final interview guide contained ten questions, while additional questions were asked to elaborate on the issues brought up by the interviewees.

After reading the vignettes, participants were asked their opinion on them and whether or not they believed the situations described in them were common. They were asked about their own experience with consumers or patients who have used OCHI, and to elaborate on any negative outcomes they may have observed. They were also asked what factors they believe may lead to negative outcomes. Finally, practitioners were asked what strategies they used to prevent or alleviate negative outcomes in their practice, while health librarians were asked what strategies they believe should be used to prevent negative outcomes. Their anonymity was assured by use of pseudonyms and no personal information was included in the interview transcripts [122].

The interviews were recorded and stored onto a flash usb drive that only I had access to. Using a 'foot pedal' and a transcribing software (Express Scribe Transcription Software), I transcribed the interviews and also securely stored them. Transcribed interviews were imported into an Nvivo 11 project for qualitative data analysis.

The interviews were conducted, transcribed and analyzed two at a time [123]. No new ideas appeared to emerge during the analysis of the last two interviews so I stopped after 10 interviews.

C. Data Analysis

Using Nvivo 11, I imported the transcribed interviews after anonymizing their names in the transcripts. I coded the transcripts from the interviews with practitioners and librarians into themes identifying types of negative outcomes and preventative measures. Similar to the first stage, a deductive-inductive analytical approach was adopted [41].

Before I started coding, following the deductive approach, I used our conceptual framework and literature review to create a coding manual of the types of outcomes (similar to consumers' interviews) both positive and negative. The types of outcomes were also those identified in the literature review, such as becoming more compliant with a management plan.

While coding, following an inductive approach, if a new type of use or outcome was identified in the transcript that did not fit into an existing code in the manual, a new code was created for that theme. Moreover, new codes were created for any preventative measures suggested by the interviewees at this stage. This included any strategies used by practitioners with their patients to prevent negative outcomes, or suggestions made regarding online consumer health information in general. After completing all the coding, I then discussed my coding manual and coding results with my co-supervisor until a consensus was reached. The final coding manual is in Appendix V. Themes were identified and described, each theme describing a "coherent and meaningful pattern in the data relevant to the research question"[124].

Reflective practice by the interviewer

Following the standard of practice in qualitative research, I kept a reflexive diary throughout the data collection phase [131, 132]. Before each interview, I took brief notes of the participant based on either the short questionnaire responses (in Stage 1) or my knowledge of their profession and location of practice (in Stage 2). I used these notes to personalize my questions for each interviewee. During the interview I also took brief notes of my thoughts during the conversation, as well as any points made by the interviewee that I thought were relevant and needed more exploration. This was done to help me clarify the purpose of specific questions. After each interview I took further notes of the main ideas while they were fresh in my mind, and highlighted any specific idea I felt I should then add to the interview guides. For example, after the second interview in Stage 2 where the idea of alternative medicine and the idea of the anti-vaccination movement were mentioned, I took note and added a question about each in the following interviews as they led to a deeper discussion on potentially un-reviewed OCHI.

Ethical considerations

This protocol was approved by the Ethics Review Board at McGill University before recruitment of participants (IRB Study Number A04-B21-15B). There was little risk to participating in this study. One ethical consideration was that any consumers with mental health issues were vulnerable and potentially at risk of developing negative complications if interviewed. To avoid recruiting vulnerable participants, I included a screening question in the recruitment tool (Are you currently on any long-term medication or being treated for any chronic conditions?). Moreover, I asked the same question at the beginning of the phone interview. As I am an MD by training, I believe I was able to assess their mental capacity before beginning the interview, and stop the interview if needed. There was a compensation for time for consumers, in the form of a $20 e-gift card to a retailer of their choice.

When consumers (through social media), practitioners and librarians (through personal contacts) agreed to participate, I emailed them the consent form. The consent discussion took place at the beginning of the interview, and their verbal consent was audio-recorded (in phone interviews with consumers) or their written consent was obtained (in in-person interviews with practitioners and librarians). The interviews were completely confidential, and audio-recorded for later transcription, but all personal details were omitted in the analysis. I replaced names with a pseudonym, and transformed any information that might identify interviewees. The interviews were recorded to be transcribed for analysis and to help me to clarify my notes as needed, and then the recordings were destroyed.

Participation in this study was completely voluntary. The information will remain confidential: no identifying information will be published in scientific articles or disclosed during presentations. All data study is being stored on a password protected external hard drive for the duration of the study, and any paper copies are securely stored. Only my supervisor and myself have access to this data. Data will be retained for 7 years after publication as per University policy stored securely, on a USB key that will be stored in a locked file cabinet.

In addition to ensuring the above ethical considerations and disclosing them to the participants, I was mindful of the researcher-participant relationship during interviews [133]. I was careful to provide information on the objectives and purpose of my study, and why they were selected as participants in either stage. I also explained how the information derived from the interviews was to be used (specifically to identify and describe negative outcomes and preventative strategies). This was clarified at the beginning of the interview and any further questions or concerns were addressed.

VI. Results

This section is structured into two sections, which correspond to the two empirical stages of my investigation.

Stage 1. Consumer Perspective

In the first stage of the project, 19 consumers of OCHI were interviewed (table 2). Hereafter, I use pseudonyms for participants, which protects confidentiality and humanizes their account of social life [122]. Fifteen of the participants (79%) were between 18 and 24 years old, and fifteen were female (79%). All had indicated that they had experienced both positive and negative consequences of using OCHI. The phone interviews lasted an average of 15 minutes. The interview results revealed when and how participants looked for OCHI, if they were able to understand it, and how they used the information they found. They also described their experiences after using the information, specifically any negative outcomes. Finally, they discussed their ideas for preventing negative outcomes and avoiding potential pitfalls following the use of OCHI. These results are divided into themes and subthemes as derived during the analysis.

Table 3 Participants in Stage 1

Pseudonym	Gender	Age group
Alan	Male	18-24
Betty	Female	18-24
Cara	Female	18-24
Dina	Female	18-24
Ella	Female	18-24
Fred	Male	18-24
Gina	Female	18-24
Harry	Male	25-34
Isabel	Female	45-54
Jenny	Female	18-24
Karen	Female	18-24
Lara	Female	25-34
Mariah	Female	18-24
Nathan	Male	18-24
Pamela	Female	18-24
Rita	Female	18-24
Sarah	Female	18-24
Tamara	Female	18-24
Vanessa	Female	25-34

My research questions are focused on negative outcomes. Therefore, in order to guarantee the quality of the data I needed to frame them in line with the whole experience of consumers. Therefore, to allow me to make more sense of negative outcomes, I explored the context of OCHI seeking and use before specifically exploring negative outcomes.

Theme 1. Motivation for searching for health information online

This theme explores participants' reasons for searching for OCHI. Consumers would search for information for themselves or for other people.

Subtheme 1.1. Searching for information for themselves

The majority of the participants in the study clearly noted that they used to search OCHI for themselves when they were not feeling well, or when they identified a new or unfamiliar symptom. As noted by Alan: *"When it is something that I cannot explain, like I have multiple symptoms and I don't know if all these symptoms are related, unrelated…"*

Subtheme 1.2. Hypochondria

In two interviews, the participants described themselves as 'hypochondriacs' who would find themselves looking for health information online frequently.

> *"I'm a little hypochondriac, I mean literally last night I was feeling nauseous so I started to google, so anytime I'm feeling an odd symptom. I'm very aware of how my body feels so anytime I feel something is abnormal and I'll look up those symptoms to see if I have anything, from nausea and headaches to weird circulatory feelings." - Rita*

Subtheme 1.3. Searching for information for someone else

Occasionally participants stated they looked for OCHI not for themselves but for other people's health questions:

> *"Last time I looked up stuff online was for my grandfather. He suffered from Parkinson's and ended up passing away because the hospital kept him bedridden and he got infected bed sores, with a horrible spiral from there. IT was the hospital's fault and we were looking for alternatives." - Nathan*

Theme.2 Strategies for searching for information online

In this theme I report the common strategies adopted by participants while searching for OCHI.

Subtheme 2.1. Using a search engine (Google)

The most common response was that participants entered their symptoms into a search engine: *"I usually google either my symptoms if I don't know what it is, or if I have an idea of what it might be then I'll google that."- Betty*

These participants had no preferred websites and would read whatever appeared on the Google results pages:

> *"I don't have any favoured reputable sites so I'll just google symptoms because I don't know where I'm going at this point. I'll probably find 3-5 different descriptions and go through it, scan it, and if they seem to say more or less the same thing then I'll go with whatever I read. So essentially it's whatever pops up on Google" - Harry*

> *"I would just google and probably click a bunch of websites." "How do you chose which websites to open?" "Usually the ones that come up first."- Jenny*

Subtheme 2.2. Using a renowned institutional medical website

Specific sites that were mentioned were WebMD, the Mayo Clinic website, the John Hopkins Medical School page, and medicine.net: *"I just google but the ones I usually end up in are WebMD or mayo clinic, I think if you google something those are the first ones that show up anyway." - Rita*

> *"It's the Internet so a million billion sites show up, with all your symptoms telling you you're totally fine or you're going to die. So usually I try to look on the John Hopkins medical school page, journals run by mostly reputable sources, and WebMD because they usually have a lot of information you can sift through." – Ella*

Subtheme 2.3. Using websites or forums with patient experiences

They also mentioned that they preferred sites that had peoples' experiences of similar symptoms or health questions, such as Yahoo Answers and forums:

"Honestly I focus more on the forums because I feel like since they are real people and not engine describing and so can be more accurate in that sense, and so I'd rather go through forums." - Alan

". . . there are a lot of useful forums where experienced marathoners have training advice, stuff like that. When to do icing or heat, which one is better than the other." -Ella

Subtheme 2.4. Strategies for evaluating OCHI websites

Participants had certain techniques by which they judged the "credibility" of a webpage before reading the information on it: *"I usually avoid sites that are trying to sell you stuff or that anyone can edit." -Tamara*

"Actually my filtering is the same as when I'm searching for anything else online. If it looks like a decently respected source I might gravitate towards, the format of the website has an impact of whether or not I deem it worth my time to look through." - Fred

"I would involve my sister who has a background in microbiology so I would say something to her and she would say that I had to look at something reputable, because when you do a google search you can literally end up with anything and there are certain sites, like university sites, provincial/federal sites are where I should be reading and not just random sites." – Isabel

Theme 3. Making sense of the information

Based on our conceptual framework, before using the information, consumers have to find situationally relevant information, and then experience a cognitive impact where they at least understand the information they find.

Subtheme 3.1. Understanding the information found

All participants stated that they understood the information they found, at least globally: *"I understand it, I might have to do further research for specific terms, but overall I understand what they're saying." -Alan*

> *"Makes sense to me. I'm certainly not a medical professional but I like to think I have a layman's knowledge and am able to understand that." -Fred*

Subtheme 3.2. Gaining general knowledge without answering a specific question

When asked if they usually found the information they were looking for, participants explained how because in most cases they didn't know exactly what they were looking for, they were not sure of what "the right answer" was. In many cases, they acknowledged that all they wanted was to get some knowledge of the issue: *"Sometimes you don't know what is wrong or right and each case is different as well, so you have an idea globally but you don't really have the answer I guess." - Mariah*

> *"Usually I land on something, I'm usually not looking for something specific just trying to get a better understanding of whatever it is… like it's never fully complete especially when it's online and a lot of the time it's coming from people's own experiences, it's never a complete answer but it gives a little bit of insight." –Dina*

> *"I'd say for the most part I get some worthwhile info, there's a lot of stuff out there that is absolutely useless. I come with some information, whether it's exactly applicable to what I was looking for or whether it's just a nice piece of info." -Fred*

Subtheme 3.3. Not finding the answer to a specific health question

In other cases, interviewees stated that they did not usually find an answer to their question: *"No, always either the problem goes away on its own or I have to go to a doctor." -Alan*

> *"No. I would have a symptom and it would usually end with me convincing myself that I had some sort of terminal illness." –Cara*

Subtheme 3.4. How health literacy influences understanding

In the interviews, when asked about understanding the information, a number of participants stated that they had a background that allowed them an easier understanding of the health information: *"No, I can usually understand it. I feel like I may be more science and health literate than a lot of people since I have a Bachelor's degree in Science." -Betty*

> *"It usually made sense but then I worked in a hospital for a couple of summers and was on some research projects and my dad is a doctor so I know some jargon, it was easy to follow." -Cara*

> *"Yeah I think so, I did my undergrad in biology and continuing in that now so in terms of terminology that's usually pretty straight for me." -Dina*

Theme 4. Decision-making after finding relevant OCHI

Then, participants were asked to remember one or more incident where they found information online that was relevant to their health question, either in that it answered it specifically or that provided them with some knowledge of the topic. This theme explores the types of decisions participants made after they found relevant OCHI.

Subtheme 4.1. Deciding whether or not to book a medical appointment

Participants stated that the information they found helped them decide on whether or not to book an appointment with their physician: *"… knowing whether or not I should actually go to a doctor." –Harry*

> *"I wouldn't say immediately but when I have a recurring kind of problem, so I'll look at it probably before calling the doctor and making an appointment." –Isabel*

> *"Basically if I see a lot of pages that say it could turn into something worse or that it's a sign of something, not one random page, then maybe I'll consult a doctor." –Mariah*

Participants mentioned that they tended to wait a few days to see if their symptoms "went away on their own" before seeing their physician:

> *“I sometimes wait a couple of days to see if the symptoms go away like they said they would, but I usually take the info with a grain of salt, but if what I'm feeling continues to correspond to what it says online then I will take it to my doctor.”* - Karen

Subtheme 4.2. Postponing a medical appointment due to limited access

When participants stated that they had limited access to a physician (they were out-of-province students and their physician was in another city, or they had to wait for days/weeks to get an appointment with their physician), they explained that they were hoping for an answer that would allow them to avoid a clinic encounter altogether: *“My doctor is in Ontario so I can't see her quickly. . .”* - Cara

> *“IT's not even that, it's that you have to wait so long now to get an appointment that if I can home remedy it that's how I sort of look at it.”* – Isabel

Subtheme 4.3. Making a health care decision

Participants also mentioned using the OCHI to make a decision regarding their health care. They explained how they would only make a decision if it did not require any drastic steps *“. . . or maybe if it is small home remedies or tricks that they give.”* - Mariah

> *“Usually if it's something like I can change what I'm eating, I follow if it doesn't seem to extreme or too hard to do. If it's something that seems a bit ridiculous then…”* - Tamara

However, participants seemed to be prudent about making any decisions based on what they read, and would follow it if the symptoms described matched theirs.

> *“It depends usually on how consistent the symptoms are with what's online. I would follow the advice if most of the symptoms fall in line with the diagnosis on the page.”* - Sarah

> *“I'll certainly take most of it with a grain of salt but the only time I would do anything with it either in going to see a doctor or changing something about my habits is everything I’m coming across corresponds to what I might be dealing with.”* - Fred

Subtheme 4.4. Stopping a medication

In other cases, it involved stopping a medication based on the side effects mentioned online: *"I've looked up stuff like side effects of birth control pills if I'm worried or more emotional, I'll see if that is one. I've actually gone off [pills] because of that."* - Jenny

> *"In May I was taking Advil too much, almost every day, and u start to get rebound headaches so I googled these headaches and saw that you're not supposed to take Advil every day and that can happen, and then within a couple of days I was completely back to normal." –Rita*

Subtheme 4.5. Discussion in a physician encounter

Another way participants used the information they found was in preparation for a physician encounter where they specifically brought it up in the clinical encounter: *"Some things I'll bring up when seeing my physician and get their advice on it." -Dina*

> *"Usually when it's a skincare issue, it [online health information] is always incorrect and the doctor would say that's not really the best solution and we would try an alternate thing. Obviously not everything on the Internet is true."* - Pamela

Subtheme 4.6. To confirm a physician's diagnosis

Participants mentioned that they would avoid mentioning that they had found something online, and would instead wait for the physician to suggest their diagnosis first:

> *"I don't think I've ever explicitly said, I looked this stuff up online. With her after explaining how I'm feeling, and she said this is what it could be and if I have an idea in my head, I don't mention it until she has said something because I don't want to conflict with her diagnosis, probably not, but I would use the info I found. I tend to read a lot about how our bodies work and I like to believe that some of the things I read do help me, so I might mention it to her." - Rita*

> *"Yes, I have symptoms and look them up and if I find what I think it is I go to the doctor and I'll let the doctor suggest on their own but I'll kind of suggest that this what I think it could be, could you confirm that for me or not?"* - Sarah

Theme 5. Positive outcomes of using OCHI from a consumer perspective

While the main focus of the study was on the negative outcomes of using OCHI, interviewees also mentioned the positive outcomes they experienced. This was expected as the sample from which participants were selected had all indicated in the recruitment survey that they had experienced both positive and negative outcomes.

Subtheme 5.1 Requesting a test to aid diagnosis

In one case, digging for information in marathon forums helped one participant understand which test to ask her physician for:

> *"I'm a long distance runner and anemia is really common for high school girls, and this was in my junior high school a few years ago. . . I got all the symptoms I found online and after I read all those I though this is exactly what I feel so I went to my doctor and asked for blood tests, and my coach recommended this as well . . . they didn't find an iron deficiency so I just kept going and thought maybe I feel awful for no reason. And then my mom and I researched this a lot because I kept getting slower . . . actually found that when you get a blood test it's really common for female athletes to get a ferritin test that they won't do on a typical blood test if they're looking for anemia so I went in and got another blood test and it turns out I was ferritin deficient so I couldn't use any of my iron so that ended up being beneficial. It's not a very common topic, most medical sites only include anemia, so I found it on a distant runner's blog and it's apparently very common but you have to ask for that test." - Ella*

Subtheme 5.2. Feeling reassured about a physician-recommended management plan

In another interview, one participant stated she believed looking for information online helped her make a more informed decision between choices of surgery.

> *"Looking back over the last year, I eventually had a hysterectomy, and I feel like if I hadn't kept looking, I probably wouldn't have been so persistent because the doctor offered me laparoscopic surgery at first, and I went back and started reading because I had some issues 3 years prior and after reading about having a hysterectomy, that to me seemed like the best way to go." – Isabel*

Subtheme 5.3. Being better prepared for a clinical appointment

Participants said they felt that, even if the information online was not completely relevant or reliable, they still felt better prepared and informed for their clinical appointment after reading it: *". . . but in the end it gave me a lot more information to have a very informed discussion with my specialist." -Harry*

> *"Recently I had a UTI so I didn't know what it was so I looked up the symptoms online and thought that was probably what it was, and so I was able to better communicate it to the doctor instead of just going in with a bunch of symptoms." -Karen*

Theme 6. Negative outcomes of OCHI from consumer perspective

Finally, participants were eventually asked to remember specific incidents that lead to a negative outcome or provide a more general description of what that negative outcome could be. I identified three main subthemes.

Subtheme 6.1. Increased worrying

The most commonly reported negative outcome was increased worrying (in 14 out of 19 interviews). This was reported in varying degrees, where some participants expressed it as a minor nuisance, while others described having panic attacks and anxiety problems over the information: *"Sometimes it is anxiety inducing. If you can't find something that's a good match for what symptoms you're having or if you find something that is a good match that isn't so pleasant."-Betty*

> *"Yes, stress probably. I would be a bit scared to see the doctor because I kept thinking I looked it up online and if it was an awful disease, I'd say well it's online and probably not true so I'm not going to go to the doctor and just ignore it."-Karen*

Participants stated that they were aware that perhaps the information they found online was exaggerated or extreme, or not related to their symptoms but they still experienced increased worrying as a result of seeing it:

> *"I think sometimes the stuff online can be a little bit extreme in terms of what actually gets shown, like the spectrum of the condition, sometimes there's that added paranoia or anxiety*

> *that comes with reading things that are probably worse than what I have. Or if it's something that doesn't have an easy treatment, or something that I'm dealing with that's not very well covered online, that kind of leads to anxiety or a more negative relationship with the information where the absence of the information." –Dina*
>
> *"In a case when despite all of rational understanding of the fact that this online search is not up to par with true health care, there's certain times where there's anxiety due to the overblown online diagnoses that are out there."-Fred*
>
> *"Overall, there is an over-reaction, I think that's the main thing, panic and I think there is also a confirmation bias, you look at the Internet, you think you are sick and then decide I am really sick, and you have nothing." –Alan*

A participant described one incident where looking for information online had prompted a vicious cycle of worry:

> *"I just started birth control pills . . . and one of the side effects is DVT [deep venous thrombosis] and I don't know if the chances are high in a healthy person but also if you're taking it for a long time that would be the case so I had only been on it for a couple of months but I had had weird feelings in my left legs and decided that when I go home over break I would go to my doctor and tell her about it. So I was googling DVT and you can get a pulmonary embolism if it travels up your leg to your lung, so of course I start to feel I might not be able to breathe and I got mini panic attacks and I had to call my mother and she had to tell me to calm down so sometimes I will have a symptom or feeling but maybe the way I react isn't always good, I've been working on it , but I tend to get very anxious about it and really psych myself out and have sort of panic symptoms because of it, and usually there's nothing wrong with me but it's my automatic reaction." –Rita*

There was one participant who had such a debilitating outcome of using OCHI that it has led her to stop looking at health information online. This participant's interview lasted longer than most interviews, and she had a lot to say on the topic. Her father was a physician, she worked in a hospital for many summers, and stated she was aware of medical terminology. Her experience with OCHI last summer led to such anxiety that for six months she blocked the health information websites she was frequenting almost daily. Her story is as follows:

> *"Yeah so what I would do, last summer I had some sort of unidentified health problems which later lead to really bad anxiety. I was going online and convincing myself I had a variety, like I would have a leg cramp and I would be like, 'Oh I must have bone cancer or something'. . . it got to the point where for 2 weeks I was having panic attacks almost every other day where I would convince myself I had a terminal illness based on the information I looked up on the Internet. And I worked in a hospital and that didn't help either so I did end up going to ER twice just being like there is something wrong with me and they look at me and say no, you're fine. And I just can't go on the Internet anymore . . . So I blocked [the websites] on my computer for 6 months." –Cara*

Subtheme 6.2. Tension with family members

A new theme identified by one participant was the creation of tension between family members as a result of one of them using OCHI in their own or in their child's health care:

> *"One of my aunts that I'm really close to takes online health info way too far, she stays with us a couple of weeks every year with her son and everything online, she follows, it doesn't matter where it's from which is horrible because the Internet has all sort of things… for 5 years my cousin's life had all the random health natural remedies online, never doctors, it was so bad. It was disturbing when we found that when he would have an infection she wouldn't take him to a doctor but make him drink honey... This situation caused stress between family members worried about the information she used." –Vanessa*

The participant elaborated on how her family would try to educate the aunt on OCHI and how this eventually may have swayed her mind on its credibility:

> *"It's been interesting as she had another baby, and now her research has become moderated and is not so extreme… She's became a little less naive as she's seen that people can post whatever they want. I always try to see if sites have actual backup for what they say."- Vanessa*

Subtheme 6.3. Postponing seeking medical help for a health problem

Participants mentioned that finding information online led to them postpone or avoid seeking medical help altogether. One participant reflected on this point and stated the following:

> *"Whatever you find tends to be biased, you find what you look for, and if you're looking for, and occlude things that tell you the opposite of what you are looking for. So in my case I might have valued a lot less information that said my condition was very serious and valued more heavily information that said it was potentially curable using homeopathic remedies or whatever so that can be very negative in terms of effect." –Harry*

A participant avoided going to a clinic once she was reassured about her symptoms online:

> *"What's happened before is all my symptoms match a virus going around I read about it and I thought yeah this virus has been going around in my area and it's nothing, it will, blow over in a week, I don't need to miss class to go to a doctor's appointment and then I ended up going to the doctor and it ended up being an ear infection and a sinus infection and it turned into 2 months of being miserable…" -Ella*

Another participant wanted to avoid the emergency room so followed some advice she found online to cure her symptoms, and unknowingly delayed diagnosing and treating her underlying problem.

> *"… Because I was so sick I couldn't think of going to the doctor, and the thought of going to the ER and waiting so long. SO I was just trying to stop the vomiting and calm my stomach down then I ended up with advice that was applesauce, banana and dry toast… I ate that for 2 weeks. When I went to the doctor it turned out I had an allergic reaction to some antibiotics I took and it did something to my liver enzymes. And it turns out I should have gone right away…Well that was it, because I hadn't looked, I would have just gone to the doctor as sick as I was. IT's available so you sort of prolong it."-Isabel*

For another participant who was recommended surgery as a management option for his condition by his physician, online information recommending an alternative was more appealing.

> *"And so I'll explain, basically one of the tubes connecting to or from my kidney was just blocked up. And there are explanations or remedies on the Internet that said this pressure can*

> *be alleviated by doing this, this, this and this. It made it sound like it was a lot less serious of a problem that it actually was. So I said Ok, doctor wants me to get surgery but wasn't really insistent that I needed to get surgery and the Internet says that if I drink more of this kind of tea and if I go to Chinatown and get these kinds of pills then I don't really need to get surgery. But then again I think I had a closed mind when I came in and the doctor said you need to get surgery, and I was like 'I'm 20 I don't need surgery, that's crazy', so it kind of re-enforced my position which was, I don't need surgery." –Harry*

In summary, adequately framed in the whole process of searching health e-information, OCHI consumers participating in this study identified three outcomes as negative due to their use of the information. First they described increased worrying as a result of finding 'scary' or worse-case-scenario information that might or might not be relevant to their symptoms. Second, a tension in the relationship with a family member was described as a result of the latter's use of potentially harmful OCHI. Finally, consumers described how OCHI may lead them to postpone seeking medical help for a health problem, or to altogether ignore their health problem which may have serious health consequences.

Theme 7. Strategies for preventing negative outcomes of OCHI from a consumer perspective

This theme explores strategies that consumers described using while handling OCHI or potential advice they would give for anyone reading and using OCHI.

Subtheme 7.1. Be aware of limitations of OCHI

One of the ideas that was mentioned in multiple interviews was the awareness of the limitations of OCHI, and that it was necessary to manage expectations regarding its reliability and its relevance to individual situations. One participant explained how her perspective of OCHI was that while she was aware it was non-specific and incomplete, she looked for it to be more informed and prepared for a clinical encounter:

> *"I think knowing that no information is ever going to be fully complete, and… everything is so specific to a given body, and just having the perspective not to take anyone's source of info as the ultimate truth, that helps a bit. And I think having accessibility to different resources of*

> *info that also helps, makes the experience a little more neutral and informative. In the end I'm just looking for information and not necessarily solutions online, just so I can be a bit more prepared."- Dina*

Another participant mentioned the same idea, and how he tried to stick to his common sense:

> *"I would say that you really have to re-inforce stick to your rational nature that this is a subpar source that cannot feasibly take into account all the specifics of your situation, and you really have to push away any of those initial irrational thoughts that come out."- Fred*

One participant explained that after many negative experiences with OCHI, she would only now only search for OCHI once a diagnosis was made by her physician, and only to be better informed on that condition:

> *"… the problem is that it's so easy to go online and diagnose yourself with stuff and sometimes it's great if you have a health problem that was already diagnosed by a professional to read details that they may not have had time to get into but if you don't know what's wrong, I really think it's a slippery slope because once you start it's really hard to stop."- Cara*

Another example of how to deal with the limitations of OCHI was given by a participant who asked her physician for a specific blood test after reading about ferritin deficiency in a runners' blog:

> *"I think just being very careful what decisions you make based on online health information; you have to weigh the consequences of the advice you're going to take against possible outcomes. In regards to the blood test for me, there was no consequence for me getting a blood test done so it wasn't as if I was going to harm myself if I followed the advice. So be careful about where you get the info and if you end up following it without a physician."- Ella*

An older participant compared OCHI with information she would look for in family medicine books for her children growing up except it was much quicker and convenient when one was feeling sick. However, she was also aware of its potential to do harm:

> *"You have to be careful, when you do a google search you get a ton of stuff there and sometimes rewording your search you get different things so you want to be reading the same thing and not doing something that could do more damage than good." Isabel*

Subtheme 7.2. Reliable and relevant sources of OCHI

Participants also made suggestions on how to make the information more relevant to their situations: *"Maybe you have a bunch of symptoms, maybe a percentage like 90% of people who feel this don't have anything or something like that…" - Alan*

> *"I think there are already doctors online, but I don't know maybe something more precise because Web MD can be precise but it's not that precise, like you can have just normal back pain and it will direct you to kidney failure." - Lara*

> *"I get tired of seeing good sites with bad info, or I guess the person wasn't having the same problem as me. I wish it couldn't be anyone who could edit it anywhere all the time, like if there was a site where an actual doctor was posting. You get a lot of home remedies that don't work. I guess a solid site that could be reliable." – Tamara*

Subtheme 7.3. Discuss OCHI with clinicians or members of social network

Participants were quick to point out that, while their first source of health information was the Internet, if they were truly worried about a certain health-related issue, they would discuss it with their physician or with people in their social circle.

This clinical encounter may be scheduled after finding a relevant piece of OCHI that required an intervention, as illustrated by the participant mentioned earlier with the ferritin blood test:

> *"I'm lucky to have a good doctor that I can see right away for any medical decisions. Once we found the article about ferritin deficiency, we brought it to the doctor he agreed right away to get the test because he couldn't think of any other cause for my symptoms." – Ella*

Two other participants recommended going to their physicians' office if they had a valid concern, due to the unreliable, unspecific nature of OCHI: *"If it's possible to talk to your doctor, at least to know the next steps." -Karen*

> *"Just really stressing about, but nothing so negative. I keep in mind that it's on the Internet, so if I was really stressed I would go talk to a real person. I am skeptical of the information so if I was worried I would go talk to a doctor." - Jenny*

Similarly, one participant would ask her mother who was a nurse for advice on any worrying symptom after conducting an OCHI search.

In one interview, the participant had limited access to her own family physician so would find it easier to ask her social circle for advice after finding worrying OCHI, and before consulting a physician:

> *"My own solution is asking family and friends if they have answers and for their opinion, if they think I should consult a doctor then I probably would. The biggest problem is how debatable or trustworthy the information is, even on medical websites it depends on every person's case, it's not specific to you, not like consulting a doctor"- Mariah*

Another participant with similar limited access to a family physician recalls calling the Telehealth hotline and speaking to a nurse about her concerns:

> *"One thing I recommend is calling Nurse hotlines, because as a student at McGill it's so hard to see a doctor especially if you're out of province so when I had my rash I decided to call the nurse hotline and not just get freaked out by what I found, and I found that was helpful, she told me what kind of care you should seek instead of go to the ER now. They're not allowed to diagnose you over the phone but there should be some form of personal interaction about your symptoms instead of just reading online and suddenly you have cancer." Sarah*

Subtheme 7.4. Follow physician provided OCHI or search parameters

One participant had an experience where, while conducting a renal scan, the technician made a provisional diagnosis after some prodding from the participant. In the two weeks between the scan and his encounter with the specialist, the participant conducted daily online research on the condition mentioned by the technician. At the encounter with the specialist he was informed of a completely different diagnosis. His research, however, allowed him to have an informed discussion with his physician. As a result, the participant explained how he feels that there may be a way to reduce anxiety while waiting for the diagnosis or the results of a test:

> *"… but also if there is a 2-week delay between getting a scan and seeing the professional about something that is serious, you should be provided with, you know, here are search parameters that you should look up that are neutral and that might give you content to reflect on so that you have an informed discussion with your doctor…. They should have said, so far, off the top of my head these are the possible conditions we have. We are going to be doing these scans in order to eliminate some of these. And maybe determine if it's this or this. If you are interested or concerned, look these up, and provide a list of potential diagnoses." Harry*

Participants identified strategies that they themselves used or that they believed would be helpful to give other consumers to prevent falling into the pitfalls of OCHI. Consumers stated that they were aware of the limitations of OCHI and advise consumers to manage their expectations when searching for health information online. They also explained the need for reliable OCHI sources provided either by their health practitioners or that featured information that was reviewed by health experts. Another strategy was to discuss the information found with a health practitioner to validate its reliability and relevance to their health question. Finally, an interviewee suggested searching only when consumers have a diagnosis or a parameter provided by a health practitioner.

Table 4 Summary of Results of Stage 1

Participant	**Theme 6 Negative Outcomes**			**Theme 7 Preventative Strategies**			
	ST 6.1	ST 6.2	ST 6.3	ST 7.1	ST 7.2	ST 7.3	ST 7.4
Alan	√				√		
Betty	√						
Cara	√			√			
Dina	√			√			
Ella			√	√		√	
Fred	√			√			
Gina	√						
Harry	√		√				√*
Isabel			√	√			
Jenny	√					√	
Karen	√					√	
Lara	√				√		
Mariah	√					√	
Nathan							
Pamela	√					√	
Rita	√						
Sarah			√			√	
Tamara			√		√		
Vanessa	√	√*					

**These themes were new and mentioned by only one interview each.*

Stage 2: Practitioner and Librarian Perspective

In the second stage of the project, ten practitioners and librarians were interviewed: three family physicians, two pharmacists, two nurses, and three health librarians (details are presented in Table 4). The interviews lasted an average of 45 minutes, and started after the interviewee had read the vignettes presented below. As per the sequential design of this study, they were first asked about their opinions on these vignettes, and whether they believed these scenarios were realistic based on their experiences. They were then asked to elaborate on their experiences with patients and consumers using OCHI, to list any negative outcomes they had witnessed, and to describe the strategies they themselves use or propose for preventing these negative outcomes. During the interviews the participants would also give their opinions on OCHI in general, list any positive outcomes they had witnessed, and describe specific areas where OCHI can be specifically problematic (for example, information on natural herbal supplements). These results are divided into themes and subthemes as derived from the analysis.

Table 5 Participants in Stage 2

Pseudonym	Profession	Work Environment
Pharma1	Clinical pharmacist	A family medicine clinic attached to a teaching hospital in Montreal.
Pharma2	Community pharmacist	A community pharmacy and a family medicine clinic in Ottawa.
Medi1	Family physician	An academic hospital and a walk in clinic in Montreal.
Medi2	Family physician	An academic hospital and a walk in clinic in Montreal.
Medi3	Family physician	A family medicine clinic in Ottawa.
Libra1	Health librarian	A hospital health sciences library in Montreal.
Libra2	Health librarian	A hospital health sciences library in Montreal.
Libra3	Health librarian	A children's hospital health sciences library in Montreal.
Nurse1	Nurse	An academic hospital in Montreal
Nurse2	Nurse Practitioner	A family medicine clinic affiliated with an academic hospital in Montreal.

Vignettes presented at the start of the interview

Vignette 1

A young 22-year-old woman who identifies herself as a “bit of a hypochondriac” usually goes online to look for health information when she has multiple symptoms and she is unsure if they are related or not. She uses information to decide if she needs to see a doctor or not.

On one occasion, she had pain near her ribs and pain with “breathing”. After checking online, she found “scary” diagnoses of similar symptoms and decided to go to the emergency room. After waiting there for a few hours, she was told it was nothing and went home. This happened a few times.

She feels that if there was more specific information online, or lists of the “most common diagnoses” for each symptom, she would worry less about her online findings.

Vignette 2

Mark is a 32-year man who usually looks for health information online when he has a new unfamiliar symptom. He uses information to decide whether (or not) he needs to see a doctor, and to find possible explanations for his symptoms. The information helps him reflect on his lifestyle and determine if there are any changes he needs to make.

On one occasion, after suffering from abdominal pain for months, his family physician requested an ultrasound. During the ultrasound, and after some probing from Mark, the ultrasound technician suggested it may be a polycystic kidney causing his pain. Since his follow up appointment with the specialist was weeks away, Mark decided to do as much research on the topic as possible, which lead to increasing anxiety over this diagnosis. Eventually at his appointment, the specialist diagnosed him with a failed kidney and not polycystic kidneys, which while severe, was still a relief for Mark.

Although in this case Mark blames the technician for making an unfounded diagnosis, he feels doing so much research on the topic allowed him to have an educated discussion with the specialist during his appointment.

Vignette 3

Sarah is a 26-year-old woman who was diagnosed with epilepsy. Her doctor prescribed Depakene as the best treatment and she started using it. Then she started getting side effects from this medication.

After looking online for health information on this issue, she found that there were complementary and alternative treatments for epilepsy like reiki and yoga, as well as herbal remedies, dietary supplements, and homeopathic treatments. She read testimonies by other people who had used these alternatives other than the Depakene and decided to perhaps try following them instead.

She feels that the information she found was biased, “you find what you look for”. She admits that while looking for information she might have valued a lot less information that said she needed to take the Depakene, and valued more heavily information that said epilepsy was potentially manageable alternative and homeopathic remedies.

Theme 1. Types of OCHI

Participants had experiences with different types and topics of OCHI depending on their profession, the location of their practice, and the types of patients/consumers they saw.

Subtheme 1.1. General health information

Physicians reported dealing with diverse topics (such as medications and their side effects, chronic and acute medical conditions, and diagnostic tests) from various sources (reviewed online medical resources, patient forums, blogs, etc.):

> *"I saw a patient at the walk-in clinic who had gall bladder stones and went to the emergency room and they did an ultrasound and confirmed it but reassured her that they'll put her on the list to see the general surgeon . . . but I think she had done a lot of reading online on the potential complications of an obstructed biliary stone . . . and waiting was too stressful because she had read about other people's horror stories". -Medi2*

> *"I once saw a patient who had a dry cough and nothing else and came into an appointment because her friend had posted on Facebook that she had pneumonia." -Medi3*

Nurses, on the other hand, are more traditionally involved in patient education, and therefore tend to be more exposed to OCHI on general health information rather than specific or specialised health conditions:

> *"Patients tend to discuss information related to lifestyle rather than what they discuss with their physicians which is related to medications and presentations, and I find that area is worse in a sense in terms of negative outcomes because there is a lot of misinformation." – Nurse1*

Pharmacists were more exposed to OCHI covering medications and their side effects, and herbal products or supplements: *"I work in a health team in a primary care clinic, I would say the majority of discussions with patients using online health information is either herbal products or vitamins." – Pharma2*

> *"As a pharmacist, my area of expertise is medications. With regards to natural health products, I have my opinion on them, I'm not against them . . . I try to explain that medications are more regulated than these products, and that just because they're natural it does not mean they are safe."- Pharma1*

Subtheme 1.2. Forums and patient-sourced information

Health librarians are traditionally health information providers, so are not necessarily exposed to patients bringing in OCHI. They were, however, very familiar with the different sources of OCHI available, specifically patient forums, and were aware of its pros and cons.

> *"It's very true that you find what you look for. There's always going to be a bias in what you look for. If you want to find a link between hallucinations and a certain type of drug, chances are you will find it in a forum or blog or something because you want to validate the information, you may write the question in a forum and someone will answer, and that's not too bad, crowd sourcing, when you want to find that someone else has had a common experience with you in a non-formal way." -Libra2*

> *"There are a ton of forums online people talking about their personal experiences that certainly fills a need because you don't get that from your health professional, they don't know what it's like to live with a condition. So it can be very helpful to see other people's experiences and it may give your ideas for alternative treatments." -Libra1*

Subtheme 1.3. Alternative medicine information

One of the more recurrent themes during the interviews was the OCHI related to alternative and complimentary medical treatments and therapies.

> *"I've definitely seen people who have been refereed to me by a physician because they're been doing all this research into complementary and alternative medicine so a lot of what I have to do is spell out the risks and benefits and the fact that we just don't know a lot about them." -Pharma2*

Participants mentioned some specific examples where patients had read of an unconventional treatment for their condition online and wanted to find out if it was a viable alternative:

> *"I remember one time a woman was diagnosed with cancer and a friend of hers had told her she found some info about how baking soda could cure cancer and she came to me asking if I could find any info about that online, and I did my best and in the end what I had to tell her was that there is no evidence and what I did find online was fairly quackery."- Libra1*
>
> *"I had a patient who was relatively healthy but had high blood pressure that he treated with valerian root he had read about online . . . and so I looked it up and there was no real evidence for its effect on blood pressure." -Nurse1*

One practitioner made an interesting observation regarding patients who discussed OCHI on alternative treatments with their healthcare provider, pointing out that people who were likely to seek non-conventional health alternatives were less likely to be seen by conventional health care providers:

> *"I think it's because people who are actively doing that [following OCHI on alternative therapy] don't seek conventional health care which is important because it prevents us from having open discussions and educating them." –Nurse1*

Subtheme 1.4. Anti-vaccination information

Another topic that was repeatedly brought up during the interviews was the anti-vaccine movement and OCHI that contained controversial information on vaccines. Participants mentioned their interactions with people who had doubts about vaccines based on what they had read online:

> *"It's extremely frustrating because a lot of this anti-vaccine stuff is focused on really small risks and you have to acknowledge there might be risks and people tend to fixate on them, like there is mercury in vaccines, yes but there's mercury in food. So it can be extremely time consuming to combat that. I think that topic is the biggest and most harmful."-Pharma2*
>
> *"I sometimes see it in parents of young children who bring them in for regular check-ups . . . the biggest problem with the anti-vaccine movement is the parents who have so much*

> *information to read and they're the ones in the middle and have been made to mistrust, and I've had discussions with parents who of course just want to do the absolute best for their child and are provided with information that is so confusing to them . . . those are situations where we do a lot of education on the issue . . . and how vaccines work and the research that was done..."-Nurse1*

Once again, a participant made an interesting observation about patients who would discuss the OCHI about vaccines with their health care providers:

> *"I find that a lot of people who come in asking questions on vaccines who found them online are actually looking for information as opposed to people who come in with their mind set and I just won't take them who are more difficult to reach." -Pharma2*

Theme 2. Advantages of OCHI

While participants were specifically asked about negative outcomes associated with OCHI, they occasionally mentioned the positive consequences of OCHI from their experience.

Subtheme 2.1. Informed and involved patients

The most commonly mentioned advantage was that OCHI allowed patients to become informed and more involved in their health care: *"I circulate a little evidence summary showing it's important to have informed patients and it's tied to patient safety, patient satisfaction, adherence." -Libra1*

As one physician stated, being informed allowed patients to become advocates for their own healthcare and experts on their condition:

> *"I do feel that there a lot of positives that come from reading, and learning more and empowering yourself . . . and I believe it's better when patients read a lot and have more info . . . they should know everything about their condition . . . I don't necessarily think it's in a patient's best interest to entirely trust someone else with their health. I think nobody cares more about someone's health than the person themselves." -Medi2*

Subtheme 2.2. More productive clinical encounters

Other participants mentioned how OCHI sometimes allowed patients to be better prepared for their clinical encounter with their healthcare provider, allowing them to prepare questions and have an informed discussion:

> *"We feel that being informed helps you have a conversation and ask the right questions so I would say that would be the approach to take, to read about the potential diagnoses as a preparation for questions you might ask." -Libra1*
>
> *"A good thing is that it allows a person to streamline their questions and have an educated discussion with their doctor. The second vignette where the patient feels that doing so much research allowed him to have an educated discussion with his physician, I feel that is a good outcome in spite of the anxiety." -Libra2*
>
> *"That said, it's also sometimes important because sometimes your doctor will not share all the possibilities of what could be wrong with you and talking to others will give you that confidence to talk to your doctor if they shut you down when you ask." -Libra3*

Subtheme 2.3. Introduce a new or alternative management option

Another possible positive outcome of OCHI is that it might allow patients to discuss a diagnosis or management option that the health care provider was not aware of.:

> *"And I think probably because of the wide range of stuff they [physicians] have to deal with, it's much harder for them to keep up with every advance in every possible area, and I have been told a couple of anecdotes where patients bringing info did help eventually find a diagnosis that may have not been found otherwise. So sometimes these hypochondriac patients who do all this searching do happen upon something." -Libra1*

On the other hand, it might allow the patient to discuss with their clinician why a proposed management plan was not the best option:

> *"I had someone whose doctor recommended endometrial ablation for some stage of endometrial cancer and she couldn't find anything online about it, so I looked and looked and all I could find was this it was absolutely not recommended so I said I couldn't find any*

> *information and provided what I had found and suggested she consult with her doctor about this and bring it to their attention." -Libra2*

Theme 3. Negative outcomes of OCHI

Since the main focus of this study is on negative outcomes of consumers using OCHI, participants were specifically asked to recall their experiences with patients or consumers who had experienced such outcomes. Five themes were derived from their perspective.

Subtheme 3.1. Increased worrying

Similar to Stage 1 results, increased worrying was the most commonly reported negative outcome of using OCHI. Interviewees did not differentiate between different degrees of worrying which ranged from worrying to anxiety to panic. Participants noted that this increased worrying was sometimes as a result of something that their patient had read online, and may not be because of their actual symptoms:

> *"Yeah I think so, she was worried, she took time off work to come in to see me, and she waited in the waiting room for a while. So I have to take her worry seriously. This applies to many patients I see, where there are no actually worrisome symptoms, if they had waited a few days whatever they had would have gone away on its own. But they had read something online either after googling their symptoms or after accidentally stumbling on a piece of online information through social media for example, and they worry they might have that." -Medi3*

In other cases, they had a real diagnosed condition, and reading about its consequences online only made them more anxious:

> *"Well I saw a patient who . . . had gallstones . . . [was] on the list to see the general surgeon, there's a long list, she doesn't have to have it [gall bladder] removed immediately, she might not have to have it removed depending on if she has attacks again and how serious they are but I think she had done a lot of reading online on the potential complications of an obstructed biliary stone and that really worried her so the idea of sitting on a wait list to see what happens to see if she has other attacks and how severe they are was too stressful because she had read about other people's horror stories." -Medi2*

One librarian believed that this anxiety was due to their need for validation of the information:

> *"And sometimes what they want is a second opinion which is a very common conversation because everyone is entitled to a second opinion and their anxiety is founded in the fact that they're been doing research on their own and they need to know if what they've seen is true or not and they need a doctor to tell them." -Libra2*

Subtheme 3.2. Spending money on non-beneficial products

The final theme was derived from an interview with pharmacist who stated that his biggest frustration with OCHI was that related to herbal supplements and potentially fraudulent therapies:

> *"A lot of the herbal and complementary and alternative therapy stuff, the biggest harm to a lot of people is that it costs money and might not work... BP: I think the main consequence is that they can't afford, it's common for people who are poor to have poor literacy so will believe all this stuff they read online or Dr. Oz so they end up spending money that they shouldn't be spending." - Pharma2*

Subtheme 3.3. Strain in the provider-patient relationship

Another negative outcome reported was the development of a strain in the patient-clinician relationship following a discussion on OCHI during the encounter. One librarian described how this would occur:

> *"Sometimes professionals don't have time and they might get irritated with their patients and vice versa and it may become a very aggressive encounter anytime they're together and cut it short. Sometimes when people are too inquisitive it can feel threatening so a health professional may say they don't have time for this, these are stupid questions etc." -Libra2*

A participant explained that she would sometimes warn her patients not to believe everything they read online regarding their diagnosis, and that she would pre-emptively explain what some of the information would say:

> *"I want them to know that I'm aware of it, that I'm not ignorant, because a lot of time this OCHI can undermine their trust in your ability and your competence and they will say why*

> *didn't you tell me about this? And sometimes the reason we haven't told is because we think that it will just scare them which is true, and we do." -Nurse1*

Sometimes this strain would occur as a result of the physician not acknowledging their patient's concern, which would drive them to seek alternative health information from other sources as illustrated in this example by a librarian:

> *"Sometimes patients will come in saying they've talked to their doctor, he's not recognizing that chronic fatigue syndrome exists, they ask for complimentary or alternative therapies they can follow. And usually I tell them to consider seeking a second opinion because sometimes what they're looking for someone to listen to them, who can guide them and info online might not be enough, they need the validation." -Libra3*

Subtheme 3.4. Non-adherence to management plan

Another negative consequence mentioned by one of the participants was non-adherence to a management plan after reading something online. This was reported by a nurse participant who had experience with patients with mental health issues.

> *"I think one of the biggest ones, the area I've had most problems with is mental health, it's a huge issue and affects a particular anxiety, a patient who is going through a lot of problems unfortunately the Internet and their ability to get information is a major block to being treated. They would look up the side effects of the medications because they are more suggestible, experience every side effect of the medication and eventually stop it." –Nurse1*

She recalls another example where a patient with high uncontrolled blood pressure refused to take blood pressure medication and instead decided to take valerian root after reading about it online:

> *"He was very skeptical and didn't want to be on medication so it took a very long time to actually find out about him [taking it], and when he first told me I had never heard about it, and so I looked it up and there was no real evidence for its effect on blood pressure, and so with time while taking it and still having uncontrolled blood pressure, I was able to get him on a medication." –Nurse1*

Subtheme 3.5. Postponing seeking medical help

This is another theme that is similar to a theme uncovered in the Stage 1 interviews. Two participants recalled anecdotes with people who were reassured by the information they had found online, and did not see the need to seek medical help for their symptoms.

> *"We had a gentleman come in here [health library] and he was looking for information, and he started discussing what was wrong with him and saying he felt numbness in his leg and I said immediately let me get you a wheelchair and transport you to the emergency room. He was asking me for info about something that I clearly couldn't solve and part of my job is identifying when someone comes to me and saying you should go see a doctor or go to the emergency room." -Libra2*

> *"Actually my friend has this funny syndrome where she develops red eye every time she travels somewhere there is a hot climate. And it first happened in Greece, bilateral red eye. And since then, every time she goes in the sun she gets red eye. I've been trying to convince her she needs to see an ophthalmologist and it could be something serious, auto-immune, but she looks online and she thinks it's just allergic conjunctivitis and she chats with people in different forums on their problems of red eye… It's been over a year I've been trying to get her to see a specialist and she hasn't." –Medi2*

Similar to the first stage, participants in this stage also reported increased worrying as a negative outcome of using OCHI. This could be as a result of reading reliable but non-relevant information or reading too much information on their condition that caused them to worry about their health or finding incorrect information from unreliable websites. It was advice on these latter websites that also led to the second negative outcome reported: the purchase of useless or potentially harmful medications online. Not validating patients' information-seeking efforts or withholding information from their patients led to a breakdown in trust in the patient-practitioner relationship. Moreover, finding information that contradicted that provided by the health practitioner also led to lowered adherence to the management plan. Finally, similar to stage 1, stage 2 participants also reported that being reassured by information found online also led to consumers postponing a medical consultation for a health issue.

Theme 4. Factors influencing outcomes

In the interviews, participants were asked about the factors they believe influenced how people used OCHI and what outcomes they would experience.

Subtheme 4.1. Individual characteristics

As illustrated below, these factors were usually related to the individual characteristics of patients such as health literacy, socioeconomic standard, Internet and computer access, health status, and language preference.

> *"Definitely low health literacy but there also really well educated people who don't have a health background and can be quite susceptible to the alternative medicine stuff. In another clinic where I work we see a lot of new immigrants, a lot of them Arabic speaking, I can't work with them as much." –Pharma2*

> *"I have patients who don't have Internet access, they may not have a computer at home or be computer literate."–Nurse2*

> *"Most of the patients I see are living in poverty, so they have less health literacy and less access to the Internet. Most people have access to the Internet in 1 way or another but probably my patient population is less likely to read a lot online and feel anxious because of that. And obviously barriers are access to a computer, literacy, being able to navigate a computer and the Internet are huge barriers for a lot of people." –Medi2*

Subtheme 4.2. Information avoidant personalities

Other factors mentioned were the individual's nature, some people would prefer to have all the information available, some liked to avoid it. Some people are more prone to anxiety than others, and reading OCHI only serves to increase that anxiety.

> *"You also have to remember you sometimes have a lot of patients who don't want to know, there can be such a thing as too much information, and bad timing for the information. I always ask them how long they have had this diagnosis. . . ." –Libra1*

> *"I think if you know your patient and kind of know they're the type who would basically somaticize every side effect you're not going to go over them in as much detail, you will sort of down play them." –Nurse1*

> *"I think it depends on where they are in their medical condition. Some people have difficulty accepting a chronic condition that needs all these medications and frequent follow-ups and home care, so the patient is freaking out. And some people are anxious by nature, they always anticipate the worse so we see different types of patients." –Pharma1*

Subtheme 4.3. Access to health care services

Another factor was related to the health care system where there is limited access to health care services and a health care provider

> *"Just that in Montreal, I don't know exact numbers but around 30-40% of people don't have a family doctor, and the more vulnerable you are the more your access to good medical care decreases so I think that yes there are flaws to Internet usage to access health care, but in a system where person-to-person health care is not good or easy to access, it may be the only resource that many people have available to them." –Medi2*

Theme 5. Strategies for preventing negative outcomes

Finally, participants were asked to describe strategies they used themselves or believed would be useful for preventing or reducing negative outcomes as a result of using OCHI.

Subtheme 5.1. Provide reliable sources of OCHI

The most commonly mentioned strategy was to provide reliable OCHI resources to patients to potentially prevent exposing them to lower quality online sources. As one librarian explained:

> *"Look it's there, so instead of resisting it, let's provide high quality alternatives so we have a little more control." –Libra1*

Two practitioners explained how they first ask their patients what their resources were and, if they were unreliable, would then direct them to more reliable ones:

> *“And I will also look at where they are getting their information from and try to direct them to sources that I have personally found to be reliable for my patients. And I do often suggest resources to try to mitigate negative consequences, especially with parents in my pediatric practice to help them feel empowered when they're at home and their child gets sick or they have a question.” –Nurse2*

> *“I ask what they read and if maybe the info is not applicable to them, it is general info and it's good they're concerned about their health. But like anything else there's good and there's bad, and I try to re-orient them with more reliable websites if they're looking for medications or medical conditions.” –Pharma1*

In addition to directing patients to reliable resources, participants mentioned finding and printing the relevant OCHI during the encounter and handing it to their patients.

> *“I like idea of family doctors having their own portal of important documents and info at a patient's level of health literacy that they can kind of print out and give to patients during the encounter.” –Medi2*

> *“Definitely finding resources that would be good to recommend as alternatives to unreliable sources. If you could integrate these credible sources into you EMR because also keeping in mind that there are populations who don't have access to online information so have some print outs available. One of the EMRs I worked with had the ability to email the information to patients through the EMR and I think that's an interesting option as well without breaking clinician's privacy.” –Nurse2*

> *“And if I make an alternative diagnosis I would either spell out the name of the condition or tell them to go on the Mayo Clinic site specifically rather than Google, or I would print out the information myself and give it to them.” –Medi3*

> *“I'll recommend some of the Health Canada resources, credible things like Canadian Diabetes Society, Mayo Clinic, etc. And sometimes if someone is with me and I look*

> *something up, I'll show them the website I go to as a way to educate them about it. I frequently print out stuff from the Mayo clinic because it's patient-friendly." –Pharma2*

One physician described how she wishes she could create her own website where she could be in control of the content, and thus, be able to provide her patients with reliable information:

> *"I also like the idea of having my own website that my patients could access just so I can have documents on different subjects that I thought were important and accurate and evidence based, just have a website with a pocket full of info on diabetes in different languages and a link to the Canadian Diabetic Association. I could also include local resources rather than a patient looking at resources based in California, I could have local resources for example for smoking cessation programs." -Medi2*

Subtheme 5.2. Teach people how to evaluate OCHI

Another strategy reported was to teach people how to properly evaluate sources of OCHI to be able to separate reliable from non-reliable sources. Only one practitioner mentioned this strategy while acknowledging that it was perhaps not always feasible:

> *"I think that if more health care providers used the approach of showing people where they look for info and pointing out potential issues with their sources and that is very effective, but it is time consuming." –Pharma2*

It was the health librarians interviewed in this study that described this as an effective strategy to prevent negative outcomes of OCHI, and how these critical skills could transfer to other content:

> *"If there's one thing that can be done specifically with regards to online health info, it's educating consumers as to how to vet content because people taking their health into their own hands is not a bad thing but they need guidance at the beginning. This is something that should be embedded in the school system from the get-go, it's a problem not unique to the medical sector." - Libra3*

One health librarian explained how she would sometimes encounter consumers who wanted all the online information available on a condition even the medical literature, and in any language, claiming that they could use Google translate if necessary:

> *“So I take the time to show them the difference between a reliable website and an unreliable one, and examples of what happens when we translate something in Google translate, this result is kind of comprehensible but it's not exactly what you want. And sometimes I'll be explaining the difference between a case study and a systematic review because ultimately if I'm educating them then they'll still do a better search, even if they decide they don't want my help, they'll still be better informed, and this will hopefully improve their experience when they go online and look for information.” -Libra2*

Another health librarian demonstrated a part of their library website that tried to educate consumers:

> *“One of the things we try to do online is provide information on how to evaluate information, if you look at our selection criteria for what we include, we want to make sure it's based on evidence, is unbiased as possible and the credentials of the people developing the content has been disclosed and is appropriate and so on, so this is something I would teach as well, criteria to use to judge if it's info you can base your decision on or not.” –Libra1*

Subtheme 5.3. Discuss OCHI during a clinical encounter

Practitioners reported using this strategy in their practice to mitigate the negative consequences of OCHI. They would encourage their patients to discuss the OCHI they had found and occasionally look the information up during the encounter. As one participant stated: *“I've mostly had a more positive experience just by being open and discussing it.” –Nurse1*

In a previously mentioned example of the patient with gallstones, the physician also followed this strategy:

> *“Well in that situation I tried to reassure her and I think I pulled Up-To-Date and looked at the evidence around why we think it's safe to use watchful waiting and not proceed to surgery immediately, and I discussed with her the risks of surgery and why you wouldn't want to have the surgery unless you were sure you really needed it.” –Medi2*

Another physician did the same and explained why she thought this was a good strategy to follow:

> *"… I spend the visit explaining why that diagnosis doesn't fit their symptoms and signs. Occasionally I would order a blood test to rule out their concern if it makes sense in their condition. A lot of times patients just want to discuss their concerns which I have learned over the years to do, it makes their worry go away when they feel they are being heard rather than belittled. If I tell them yes that would make sense if you also had this and that, rather than say no there is no way you have that full stop. I understand that I won't be as worried about their health as much as they are, and I have to respect that." –Medi3*

In one case, a participant explained how after discussing the information with the patient, and finding that they were still unconvinced of her opinion, she would accept their decision:

> *"So I give small pieces of info and see how a pt. acts or reacts, in some cases you can change the pt.'s opinion but in some cases you can't. If something seems harmless, and a pt. seems obsessive, this is their life and they are entitled to harm themselves if they want to." –Medi1*

Subtheme 5.4. Handling OCHI on alternative treatments/non-conventional therapies

A separate theme was created for strategies on dealing with OCHI on alternative therapies, but the strategies mentioned were similar to those mentioned previously: providing reliable online sources, and discussing the information during the encounter.

> *"For the third vignette, we certainly don't discourage exploration into complementary and alternative treatments, we have an excellent evidence based database we can search that have knowledge synthesis of the research that shows whether a given alternative treatment is actually effective so we could have looked at maybe different remedies to show if there is any solid evidence and if it actually works and maybe there's definitely bias." –Libra1*

> *"Sometimes I would get a patient asking about an alternative therapy that they had found for their condition and that they were thinking of trying it. If it's something I had heard of before and knew of its effects I would discuss the pros and cons of using it instead of conventional therapy, and let them decide after making my opinion known. Sometimes it's something I had never heard of before so I ask them to wait until I have had time to research it a little before giving a recommendation. I try to establish a trust between us so they don't stop their current*

> *treatment without telling me. I realise that they can stop anyway and do what they want which could endanger them so I try to stay included in their decision making process.” –Medi3*

On the other hand, dealing with this type of OCHI sometimes meant educating patients on what the difference between regulated treatments and unregulated ones was, and why some of these alternative therapies would possibly be less beneficial if not also harmful. Eventually, however, the decision would be left to the patients:

> *“Sometimes I'll educate them on what medicine is and try to get them to understand that they're all medicine and some are just researched better than others, some have a longer history and there may not be any negative outcomes, but there aren't really any positive outcomes so that's how I deal with it. I leave the decision with the person as much as possible.” -Pharma2*

> *“If someone brings in something I haven't read before I try to be open minded because while we practice in the biomedical world of health, there's a lot of other health systems and practices and we're in a very multicultural city, so I ask what other health providers they've seen, and what they're seeing them for and what the goals of their treatment are. And then what I do with that information depends on if I feel what they're doing is relatively benign or potentially helpful then that's fine but if there's something.” –Nurse2*

Subtheme 5.5. Health librarians’ role

During the interviews with librarians, it was evident that they had a different perspective from practitioners because consumers would come to them with a specific information request. One librarian summarized her role as follows: *“My role is to research so they have reliable info that allows them to make informed decisions and become partners in their care with doctors.” – Libra2*

To do so they would try to fulfill the consumer’s request without bias and without assuming any medical knowledge:

> *“I had an incident where someone said 'I had a blood clot in my lung, and I have asthma, and I think asthma caused the blood clot in my lung' and I asked them if they were sure, and they*

> *said no, so we're looking if there is any possible link between these 2 topics, and not saying there's any association necessarily, and they agreed so I offered to look at causes at blood clots in general as well and they agreed. So it's a step by step process to bring someone into an evaluative state where they can look and say that maybe their assumption that may be right but we can't know that." –Libra2*

> *"For the second vignette, when people come to with a probable diagnosis and say the doctor says it might be this, this or this, I say to them it might be a good idea to wait until they have their diagnosis before going too far into learning about different. It's not that I want to discourage people but I want to make sure we have an actual diagnosis to start from. We're here so whenever you get a diagnosis... and in the meantime we could certainly help you better understand what tests are looking for but without going too much further." –Libra1*

One way in which librarians help patients is by providing them with strategies to present their information to their health care provider in a manner that will mitigate any negative consequences:

> *"I tell them to prepare some questions for their doctor based on this info and that I can help them prepare these questions. So patients need to know that . . . there are better ways to communicate their concerns so that's when I often advise them to write their questions or bring someone with them to the visit who can help them be heard, or see the patient's committee who can offer accompaniment. There are ways for facilitating that conversation and helping people to know there are options for them other than more research and more information, showing them that not all doors are closed can help lower their anxiety, even if the info is unreliable, having their questions validated can help." –Libra2*

> *"Sometimes when doctors don't have time to discuss with their patients, I advise them to ask if there is a nurse educator or someone who they can talk to, or to schedule another appointment to answer the questions, push through and plan your 'attack' in a systematic way, know what you want and write it down." –Libra2*

> *"And from the patient side, well we actually have a page in our website called preparing for your visit, we provide advice on how to approach that, and one of the things is to make a list of your questions because you may forget once face a busy doctor. And also if it's a really serious issue to bring someone with you because you might be so upset you may not be able to process what is being said to you." –Libra1*

Subtheme 5.6. Change health care provider attitudes

Participants repeatedly acknowledged that the existence of OCHI and the frequency of its use has already changed the attitudes of health care providers, and continues to do so in many ways. One health librarian described how practitioner's attitudes needed to be changed with regards to discussing OCHI with their patients:

> *"I think learning how to talk to patients and not implicitly create a hierarchy in a hospital is very important… Doctor's training is important and patients could read the same information as a doctor can and still not get the same experience. However, every patient story is important, and can add value and they are experts in their own care." –Libra2*

Another librarian described techniques that were being taught to physicians to ensure better communication during an encounter:

> *"There's definitely a time limit . . . On the side of the physician the advice is to use active listening and not interrupt because actually if you let a person talk it will take them less time to finish their story than if you interrupt and hurry them up. It also helps to ask, 'what are the 3 things you want to talk about today we may not get to all of them so let's prioritize." -Libra1*

Practitioners are aware of the fact that health information is readily available to their patients, and this has forced them to provide more information during a clinical encounter to prevent a negative consequence:

> *"In some ways it has changed my practice a little bit. I think if I know the patient is going to be able to find this information I try to tell them . . . and in some ways it's a good thing. Sometimes as clinicians we don't want to talk about these things or are afraid of how are patients are going to react but at the same time they have the right to the information but the unfortunate thing is that a lot of times they get the information after they've seen us and we*

> *don't have the opportunity to guide them through understanding it. And patients may not come to us for that because the trust has already been broken and they don't ask you." –Nurse1*

One physician described the limitations of their role as health service providers in the lives of their patients:

> *"I think patients have a right to choose the risk, like they have the right to agree or refuse a procedure, to start or stop smoking, it's their rights. So talking about preventing harms for everyone everywhere is not realistic. Should medical professionals intervene with what their patient does, I think that's impossible. What we can do is try to understand what information a patient is comfortable with." -Medi1*

Another physician explained how the spread of non-conventional health information online and its popularity among patients has forced her to challenge her assumptions:

> *"I think the anti-Western medicine movement that flourishes on the Internet or social media could tell us a lot about what the patient experience is like in Western medicine, it should give western practitioners a signal that maybe we're not communicating as effectively as we can be, turning people off for a valid and legitimate reason, what can we do to make people more comfortable and about the things we recommend? Rather than saying the root of the problem is these Internet-based crazy people." –Medi2*

Many strategies were proposed by participants to potentially prevent the occurrence of negative outcomes. First of all, similar to the first stage, participants recommended providing reliable OCHI sources that they were aware of or by printing out the information related to their clinical encounter and handing it out. A second way to ensure consumers were finding reliable OCHI sources was to teach them how to evaluate websites, either by showing them during an appointment or by guiding them to online resources with checklists on evaluation techniques. Another strategy that is similar to that proposed in the first stage is to encourage consumers to discuss the OCHI with a health care provider during a clinical encounter, to validate the information's reliability and relevance. This was important in handling OCHI about alternative and complementary therapies, where it is important to explain to consumers the difference between regulated and unregulated therapies, and how to ensure that the information they find online is reliable. In all the above strategies, the health librarians' role was highlighted, they were identified as well situated to providing reliable OCHI sources, teaching consumers how to evaluate websites, help consumers prepare the information to discuss during a clinical encounter, and find reviewed evidence on complementary and alternative therapies. One final overarching idea was that, due to the frequency of OCHI use, health care providers needed to be better trained in handling OCHI brought up during the clinical encounter.

Theme 6. General opinion of participants on OCHI

Throughout the interviews, participants would give a general opinion on OCHI based on their experience. All the participants had seen their patients, their clients, and their friends and family use OCHI. In fact, they all stated that they had used OCHI themselves in their own health care. They believed it was a permanent fixture in today's world, and an inevitable presence in the health care system: *"And for patients, 'I saw this online' is the new 'my friend told me', which I still see a lot with the elderly, although even the elderly are going online." -Pharma2*

> *"There's always going to be people coming in with their own interpretations of things and before we had Internet people would come in saying this person told me this which still happens now, 'my friend's uncle is a doctor and they said this and that' so we can only do the best we can do." - Nurse2*

Table 6 Summary of Results of Stage 2

Pseudonym	**Theme 3 Negative Outcomes**					**Theme 5 Preventative Strategies**					
	ST 3.1	ST 3.2	ST 3.3	ST 3.4	ST 3.5	ST 5.1	ST 5.2	ST 5.3	ST 5.4	ST 5.5	ST 5.6
Pharma1						√		√			
Pharma2	√	√				√				√	
Medi1	√							√	√		
Medi2	√				√	√		√	√		
Medi3	√					√		√	√	√	
Libra1						√	√		√	√	√
Libra2	√		√		√	√	√	√	√		√
Libra3						√				√	√
Nurse1	√		√	√				√	√	√	
Nurse2						√				√	

VII. Discussion

> Over the past decade, the world has become increasingly hyperconnected. We live in an environment where the Internet and its associated services are accessible and immediate, where people and business can communicate with each other instantly, and where machines are equally interconnected with each other. This hyperconnectivity is deeply redefining relationships between individuals, consumers and enterprises, and citizens and governments: it is introducing new opportunities but also new challenges and risks in terms of individual rights and privacy, security, cybercrime, the flow of personal data and access to information."
>
> Robert Greenhill, Chief Business Officer, World Economic Forum, 2012

All the participants in my study shared the common knowledge that OCHI is a part of daily routines in today's health care processes. It is a common, if not the most frequent, source of health information for consumers, and is an integral part of their health care decision-making process. Congruent with existing evidence on OCHI, participants in this investigation emphasize the fact that the outcomes of using OCHI are generally positive, especially when information sources are reliable. However, as suggested in the systematic mixed studies review conducted prior to this empirical investigation, consumers, practitioners, and librarians participating in the study all confirmed that OCHI negative outcomes exist as well. In line with Greenhill (2012), this is introducing new risks in terms of information use in primary care.

Due to the routine use of OCHI by almost everybody, these negative outcomes are an important issue. They have, however, not been examined in depth and from multiple perspectives in previous studies conducted at a community-based primary health care level. In our systematic mixed studies review, negative outcomes were reported in one third of included studies (23/66), but no study scrutinized these outcomes by triangulating the perspectives of the general population, health librarians and different types of primary care practitioners (nurses, pharmacists and physicians); moreover, none studied potential solutions. The aim of this study, therefore, was to identify these negative outcomes from different viewpoints, as well as suggest potentially preventative strategies.

Importantly, negative outcomes were reported consistently across my study: the literature review, consumers in Stage 1, and health practitioners and librarians in Stage 2. On further examination of these outcomes, they appeared to fall into three dimensions, depending on who/what was being affected by the use of OCHI. These outcomes were then regrouped into three levels: internal, interpersonal, and service-related (Table 6). From these levels emerged a new construct that best encompasses these themes (includes and frames them in a comprehensive manner): "tensions".

All negative outcomes fall under this construct. This thesis chapter section will present these levels and meaningful construct.

Table 7 Themes of negative outcomes

LEVELS	***LITERATURE REVIEW***	***STAGE 1: CONSUMERS***	***STAGE 2 : PRACTITIONERS AND LIBRARIANS***
INTERNAL	• Increased worries.	• Increased worrying	• Increased worrying • Spending money on non-beneficial products
INTERPERSO	• Worsening of the physician-patient relationship	• Tension with family members	• Tension in the provider-patient relationship
SERVICE-RELATED	• Misuse or overuse of health care services	• Ignoring (not seeking help) for a health problem	• Non-adherence to management plan • Postponing seeking medical help

Level 1: Internal negative outcomes

These are outcomes that affect the consumer alone as a result of seeking and using OCHI, and are associated with an emotional state. Internal outcomes uncovered in my study include increased worrying and anxiety. This was reported in varying degrees, where some OCHI user participants described the worrying as a minor nuisance, while others described having panic attacks and anxiety problems over the information. Although participants in my study stated that they were aware that the information they found online was in some cases exaggerated or unrelated to their symptoms, they still experienced increased worrying as a result of seeing it. This was also reported by health practitioners and librarians in my study, who also described how reading details and other patient testimonies about their diagnosis online only made their patients more anxious.

This phenomenon is well documented in the literature, and has resulted in the coining of the term “cyberchondria” [19, 92]. In one study 31.4% of the total sample experienced increased health anxiety following searching for OCHI, while another study reported that it was approximately 38% of their sample [19, 134]. It has been suggested that “challenge and confusion, and dealing with the familiar and with the contradictory, are sources or triggers of emotional behaviour in information situations" [135]. While reliable sources of OCHI are associated with positive outcomes, it remains a fact that the quality of OCHI is poorly controlled and regulated [136]. Moreover, with some consumers' lack of theoretical knowledge and ability to critically evaluate the information, this will inevitably lead to misinterpretation and unnecessary fear and anxiety [137, 138]. Another influencing factor is the individual's proneness to worry; some people are more prone to anxiety than others. One study examining the relationship between 'anxiety sensitivity' (fears of anxiety-related sensations) and OCHI use, reported that there was a relationship between exposure to OCHI and the etiology and maintenance of anxiety sensitivity [139].

Level 2. Interpersonal negative outcomes

These include any strain in the relationship between the OCHI consumer and other individuals, such as their health care provider, or a family member. Only participants in the second stage (practitioners and librarians) identified a strain in the patient-practitioner relationship as an outcome, it was not mentioned by consumer-participants. This discrepancy in reporting may be as a result of them not using OCHI in discussion with their health care provider specifically. It may also be due to a power issue that requires exploring in future research.

In the second stage, this outcome was highlighted specifically by health librarians who explained how this strain in the patient-practitioner relationship occurred when the practitioner would not acknowledge or validate the information brought in by their patient. In other cases, practitioners described how they believed a lack of trust developed when patients found information online that their health care provider had not mentioned during the clinical encounter.

This type of outcomes has also frequently been reported in the literature. Patients who have read health information online may give less credence to their doctor's opinion, and may use the information to "test" their doctor's knowledge, causing damage to the patient-physician relationship [137, 138, 140]. On the other hand, some doctors lack the communication skills or are just not updated on all the information available, and thus report difficulties in dealing with OCHI [141].

Another form of interpersonal negative outcome described by one consumer-participant in my study is in relation to family members. This occurred as a result of having one family member follow unreliable health information they found online, which has led to an individual feeling frustrated and worried. This may lead to a strain in the relationship, and may have other consequences yet unstudied.

While this type of interpersonal strain was not identified in relation to OCHI in the literature, it has been identified in relation to sharing information with family members. In one study examining the effects of discussing sexuality and contraception on mother-daughter relationships, the authors identified that a strain in the relationship may develop [142].

Level 3. Service-related negative outcomes

Any strain in the relationship between an individual (OCHI consumer or patient) and the health care system as a whole, leading to a change in the individual's use of health care services or adherence to management plans. Examples in my study included postponing seeking health care for a problem, ignoring health care providers' instructions, or replacing the health care provider altogether. This is in line with results reported in other studies. In one study, over 11% of the respondents reported that finding health information online led to them refusing or discontinuing treatment recommended by a physician or dentist [78]. Other studies also reported that participants (35% and 29.9%) would use the Internet as a health information source instead of getting a professional opinion [10, 75]. On the other hand, it was also reported that OCHI could lead to more frequent encounters with their health care provider based on the information found [65, 75, 96].

Tension: A comprehensive and meaningful construct

Across these three levels, I argue that the OCHI's negative outcomes shared a common nature, which I have labelled '**OCHI tensions'**. According to the Merriam-Webster dictionary, tension is defined as "(i) inner striving, unrest, or imbalance often with physiological indication of emotion or (ii) a state of latent hostility or opposition between individuals or groups" [143]. The term OCHI tension would therefore refer to the feeling of uneasiness people who actively search for online health information experience with themselves, with other people, as well as vis-à-vis the healthcare services. Therefore, I argue that tension is a comprehensive and meaningful construct that represent a variety of negative outcomes along three dimensions (the three levels depicted above).

Table 8 The three dimensions (levels) of the construct ‘OCHI use-related tension’

Tension	***Literature Review***	***Consumers***	***Health practitioners and librarians***
Internal	√	√	√
Interpersonal	√	√	√
Service-related	√	√	√

These three dimensions of tensions were described in various ways by the three sources examined in my study (Table 7). Based on this construct (larger theme) of tension, I conceive the “OCHI use-related Tensions” as presented in Figure 2. This conception will enrich the original conceptual framework of my thesis, and add to the scientific knowledge on the outcomes of OCHI use [37].

-

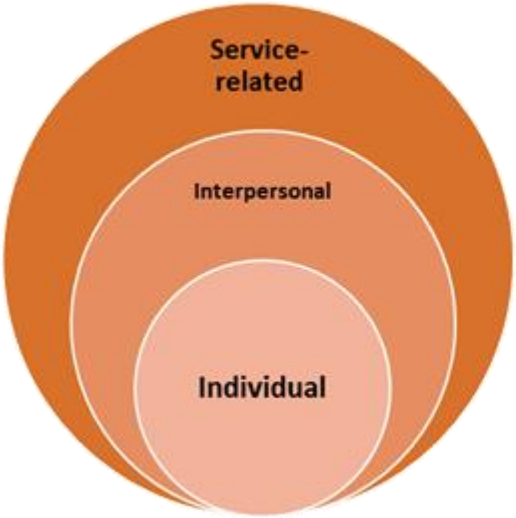


Figure 2 OCHI use-based Tensions

In the literature, there is an established link between health anxiety (internal tension) and the patient-physician relationship (interpersonal tension). Health anxious people are more prone to wrong self-diagnosis and unnecessary worries, which is likely to increase the risk of misunderstanding and frustration with their doctor [95]. They may also feel that the duration of the clinical encounter was not enough to discuss all their worries and be less satisfied with the consultation [62, 144, 145]. Moreover, there are studies that report a link between low trust in the physician (interpersonal tension) and non-adherence or mal-adherence to a management plan (service-related tension) [146-148]. I therefore propose that there is a relationship between the three dimensions of tension. This may be an interesting topic for future research.

Potential preventative strategies

A better understanding of negative outcomes experienced by primary care patients who actively search for health information on Internet is a major contribution of this thesis. But this work goes beyond, in line with Robert Greenhill suggested in 2012; I quote: "*Mastering and leveraging these transformations to maximize the positive impacts and increase resilience against the risk that information and communication technologies can bring to the economy, society, environment, and healthcare are crucial.*" Hence, after identifying the tensions related to OCHI use, several strategies targeted at different stages of the information seeking process have been identified: before seeking the information online, while searching for information online, and after finding the information online. They can be summarized into three main preventive strategies as shown in Figure 2: providing reliable sources of OCHI, teaching consumers how to evaluate OCHI sources, and encouraging OCHI consumers to discuss the information. During the analysis it became clear that the health librarian participants in the second stage provided a distinct separate viewpoint and played a very different role from health practitioners.

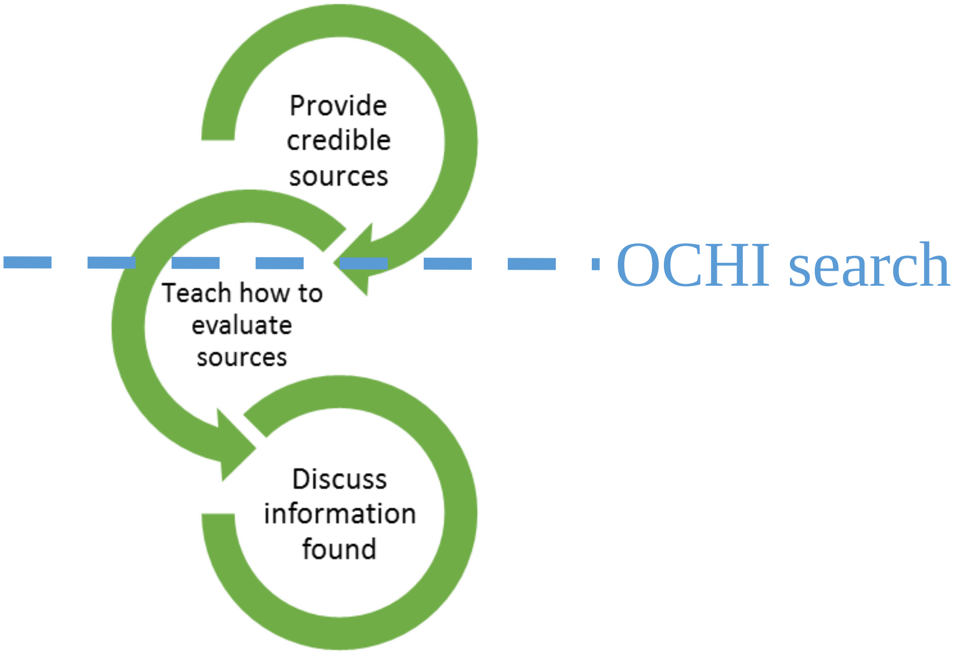


Figure 3 Strategies to prevent OCHI tensions

Before OCHI search: providing reliable sources

In this study, participants from both stages stated the need for reliable sources of OCHI. Health practitioners explained how they would pre-emptively provide patients with the names of reliable, reviewed websites during the clinical encounter rather than wait for patients to navigate on their own.

This is in line with other studies that recommend that health care providers, specifically doctors, guide patients to reliable sources of OCHI [138, 149, 150]. Inevitability, people will try to search for health information online, however, they may not be adequately equipped to deal with the vast number of OCHI resources. In one study even physicians expressed a need for training on how to navigate OCHI resources so that they are better able to recommend websites to their patients [137].

Only some health practitioner provided these sources during the clinical encounter, not necessarily on a consistent basis. Two studies that examined the clinic-wide implementation of Information Prescriptions reported positive outcomes such as decreased patient anxiety and a better understanding of the health problem [66, 67]. In general, however, it is mostly organizations, institutes or professional associations doing the effort to provide reliable health information online, such as the Heart and Stroke Foundation, the College of Family Physicians of Canada or the US National Library of Medicine (Medline Plus). A great limitation to this is social media which has become a popular forum for sharing OCHI that may be un-reviewed or have dubious origins or motives.

It is in relation to this strategy that health librarians play an important role in the provision of reliable, unbiased reviewed health information to consumers. They do this either by directly providing consumers with the information (print-outs, pamphlets, books, etc.) or by providing them with links to reliable online resources.

During the search: teaching consumers how to evaluate OCHI sources

Another strategy suggested by health practitioners and librarians was to teach patients how to evaluate OCHI sources, either by discussing potential ‘red flags’ for unreliable resources, or by showing them how to search on their computer. Once again this is an individual service provided voluntarily by some practitioners and, more commonly, by health librarians.

In the literature it has been reported that evaluation interventions (aimed at teaching “how to evaluate search results, information and source”) led to a more critical evaluation of online information [151, 152]. This education process, however, is time consuming and may not be a priority during the clinical encounter. While practitioners could provide their patients with a list of criteria for reliable websites, there are also online resources available in the form of guidelines and checklists to follow while evaluating a website. However, many consumers, especially those in a lower socioeconomic strata, may not be aware of these resources or the fact that they are not correctly evaluating resources [153]. As suggested by participants in this study, an organizational effort is needed, for example through mass media or in school curriculums.

This is another service that health librarians provide to consumers. Many hospital health libraries provide criteria and guidelines for evaluating OCHI websites, and librarians frequently guide consumers to these guidelines for future searches. They also teach consumers individually how to evaluate websites, specifically how to avoid potentially fraudulent websites.

After finding relevant OCHI: discussing the information found

Stage 1 participants in this study explained how discussing the information they found with a knowledgeable health expert often led to positive outcomes. Health librarians in the study stated that they would encourage OCHI consumers to discuss the information with health professional in their family or social network, with a nurse trained in communication with the public (such as Info Santé, a free and confidential telephone service that puts consumers in contact with trained nurses), with a health librarian in a hospital or patient resource centre, or with a health care practitioner.

This is supported by the literature; it was reported that patients simply need to have the information they found explained, contextualized or validated by an expert [10, 138]. Studies report that discussing the information they had found with their physicians had a positive effect on the patient-physician relationship, lead to more involvement in decision-making, and lead to reduction of worries [20, 26, 144]. One study reported that patients would sometimes not discuss OCHI they had found during the clinical encounter, either due to lack of motivation or forgetfulness, but would likely respond to doctor-initiated conversation [149]. For health practitioners, there are ongoing initiatives to add to curriculum and continuing education of health practitioners (for example, workshops on dealing with their informed patients). For consumers, there are initiatives to encourage them to discuss information with their providers either through the help of a health librarian who can help organize the information and questions, or applications (apps) and websites that aid in that role (for example, DiscutonsSante.ca).

There are however limitations to discussing OCHI; time limitations as there may be more important things to discuss during the clinical encounter, and there may be a barrier related to practitioner attitudes (not receptive to sharing knowledge with their patients such as all side effects). There may also be a barrier in understanding the health information (due to low health literacy or low education) or a limited social network. OCHI consumers may also not be aware of alternative resources such as health communications specialists or health librarians.

The key role of librarians

Throughout my study, the role of health librarians has been clearly distinct. They are responsible for providing reliable health information and advocate the advantages of using OCHI and informed decision making. They have experience with both consumers and health practitioners, and are aware of how OCHI is used and how this use can sometimes lead to negative outcomes. They have the expertise and training to play a role in all stages of OCHI seeking and use, and are ideally positioned to implement the preventive strategies described in this study. The health librarians I interviewed in my study were all situated inside a hospital library and all already implemented these strategies in one form or another. The integration of health librarians into the consumer's health information seeking process may ensure that the information the consumers have is reliable and suited to their level of health literacy, leading to fewer internal tensions. Moreover, their involvement may facilitate the discussion with health practitioners, leading to fewer interpersonal tensions. Finally, consumers will have situationally relevant information (with respect to their specific health question) which will allow them to make more appropriate health care decision, potentially leading to fewer service-related tensions.

There are, however, two barriers to the integration of health librarians into this information seeking process: the lack of awareness of available health librarian services and the lack of access to health librarians by the general public (due to their location inside hospitals). One potential solution would be to train community librarians working in public libraries on how to provide health information services and instruction, or at least train them to refer consumers to the local hospital-based health librarian. A study examining the role of public libraries on health reported that consumers believed the health information they found improved their health [154]. A CIHR funded study in Quebec City will seek to examine how public libraries can be involved in informed decision-making. The role of librarians in preventing negative consumer outcomes of OCHI definitely constitutes a hot topic for promising future research in health and information sciences.

Study Limitations

As any other research endeavor, this thesis presents a number of limitations. First, the majority of respondents in Stage 1 were female (79%) and younger (79% were 18-24 years old). This in in line with other studies that reported that the majority of individuals who searched for and used OCHI were women [10, 46, 59] The literature also reports that individuals less than 35 years old were more likely to be OCHI consumers [46, 58, 59]. I believe using social media to recruit Stage 1 participants may have lead to this younger population sample. A future study could focus on an older population to uncover any different negative outcomes. That said, variation was maximized in regard to other criteria, notably negative consequences of using online information. What is more, no new ideas appeared to emerge in the final few interviews, and there was corroboration after triangulation of results of the review and all interviews. In sum, participants were all key informants, purposefully sampled for their experience and knowledge on the topic, as well as their willingness to incorporate OCHI in their practice [123, 154].

Finally, whereas I conducted fieldwork and initial analysis on my own, I always counted on my thesis advisory committee methodological support, its members being deeply involved in latest phases of data analysis and interpretation.

Summary of contributions of my work and future research directions

This thesis makes two major contributions to the advancement of knowledge on OCHI. The first concerns a fine-grained identification of OCHI negative outcomes, which results from what I have coined the construct 'OCHI use-related tension' and three dimensions (three different and non-inclusive levels of tensions): individual, interpersonal and service-related. This new construct enriches the original conceptual framework on Outcomes of OCHI use (Figure 1). This proposal is original, and can serve as a foundation for future research.

The second contribution, which involves clear practical implications, refers to the strategies primary care consumers (including patients), community and health librarians, and primary care practitioners (all types: allied, nurses, pharmacists, physicians and social workers), could adopt in order to prevent the risks associated with OCHI use. Exploration of these strategies and their implementation will be part of future research.

VIII. Conclusion

The objectives of this study were to identify the negative outcomes associated with using online consumer health information (OCHI), as well as to describe any potentially preventive strategies. Negative outcomes have previously been explored from a patient perspective or from a physician perspective but rarely from both perspectives, and not from the perspective of other health practitioners or librarians. Moreover, previous studies that reported these negative outcomes reported them briefly; studies that expanded on them focused on specific populations.

To answer my research questions, I conducted a literature review on negative outcomes nested in a larger systematic review on all outcomes of OCHI use. Next, using our conceptual framework of OCHI outcomes, I designed a two-stage descriptive qualitative study [155]. It consisted of interviews with a purposive sample of 19 OCHI users in the first stage, followed by interviews with 10 health practitioners and librarians (three family physicians, two nurses, two pharmacists, and three health librarians) in the second stage. In the first stage, OCHI consumers made sense of their experiences; I created vignettes from a sample of these experiences that I then used in the second stage of interviews to stimulate the discussion with practitioners and librarians. Following a deductive-inductive approach, I conducted a thematic analysis of the interviews to identify all themes related to negative outcomes and preventive strategies.

By converging the negative outcomes identified from these four sources (literature, OCHI consumers, health practitioners, and health librarians), I conceptualized my findings in a new construct: OCHI use-related tension. This construct has three dimensions (three interdependent levels): internal, interpersonal, and service-related tensions. This new construct will enrich the original conceptual framework of OCHI outcomes (specifying the last type of outcome, namely ‘patient health outcomes’).

While the studies in my literature review did not mention any preventive strategies, I described these strategies in my empirical study from the perspectives of OCHI consumers, health practitioners and health librarians. Strategies could be implemented before the OCHI searching process (providing reliable sources), during the searching process (teaching consumers to evaluate sources), or after the searching process (encouraging consumers to discuss the information with a professional). While health practitioners can integrate these strategies in their practice, there are many barriers to this implementation in terms of time limitation during the clinical encounter, lack of training in navigating online resources, and negative practitioner attitudes towards OCHI. Health librarians, however, are ideally situated to implement these strategies due to their training and expertise, their contact with both consumers and practitioners, as well as their location inside health libraries. Future research may examine the effect of integrating part of the health librarians' role inside public libraries and with community librarians.

The main contribution of my thesis is therefore ontological as the review and interviews allowed me to define types of OCHI negative outcomes in a trustworthy manner (as a result of the convergence between results of the review and the qualitative research). I explored negative outcomes from three viewpoints: OCHI consumers, health practitioners, and librarians. This approach allowed me to achieve internal validity by describing the same phenomenon from different perspectives in a comprehensive manner, and to identify a global construct: the OCHI use-related tension. My approach is unique as our systematic review showed that only one third of included primary care studies reported fragmented patients' and clinicians' viewpoints related to negative outcomes of OCHI use (briefly or incidentally or focussing on specific populations); none triangulated the literature and the perspectives of multiple stakeholders; none studied potential solutions. In contrast, my results show corroboration between the aggregated results of previous studies and the perspectives of general consumers, health librarians and three types of health practitioners (nurses, pharmacists and physicians), and suggest preventative strategies.

References

1. ITU. *The world in 2015: ICT facts and figures*. 2015; Available from: http://www.itu.int/en/ITU-D/Statistics/Pages/facts/default.aspx.
2. CIRA. *CIRA | Canadian Internet Registration Authority - Factbook 2015 | The Canadian Internet*. 2015 10 November 2015]; Available from: https://cira.ca/factbook/current/the-canadian-internet.html.
3. Gunelius, S. *The Cost of Content Clutter Infographic*. 2013; Available from: http://aci.info/2013/11/06/the-cost-of-content-clutter-infographic/.
4. Anderson, A.S. and P. Klemm, *The Internet: friend or foe when providing patient education?* Clinical journal of oncology nursing, 2008. **12**(1): p. 55-63.
5. HLWIKI, C.c. *Consumer health information*. 2015 29 September 2015 10 November 2015]; Available from: http://hlwiki.slais.ubc.ca/index.php?title=Consumer_health_information&oldid=142405.
6. Simon, H.A., *Le nouveau management: la décision par les ordinateurs*. 1980: Economica.
7. Fox, S. and S. Jones, *The Social Life of Health Information. Report of the Pew Internet & American Life Project, May 12, 2011*. 2012.
8. Tu, H.T. and G.R. Cohen, *Striking jump in consumers seeking health care information*. 2008: Center for Studying Health System Change.
9. Prestin, A., S.N. Vieux, and W.-y.S. Chou, *Is Online Health Activity Alive and Well or Flatlining? Findings From 10 Years of the Health Information National Trends Survey.* Journal of Health Communication, 2015. **20**(7): p. 790-798.
10. Fox, S. and M. Duggan, *Health online 2013.* 2013.
11. StatCan. *Table 358-0153 - Canadian Internet use survey, Internet use, by age group, Internet activity, sex, level of education and household income, occasional (percent), CANSIM (database).* 2013 10 November 2015]; Available from: http://www5.statcan.gc.ca/cansim/pick-choisir?lang=eng&p2=33&id=3580153.
12. CEFRIO, C.f.d.i.d.o.-. *Génération @: Portrait de l'utilisation d'internet et de l'ordinateur par les aînés internautes du Québec*. 2011, CEFRIO: Montréal.
13. Pluye, P., et al., *Four Levels of Outcomes of Information-Seeking: A Mixed Methods Study in Primary Health Care.* Journal of the American Society for Information Science and Technology, 2013. **64**(1): p. 108-125.
14. Coulter, A., *Patient engagement—what works?* The Journal of ambulatory care management, 2012. **35**(2): p. 80-89.
15. Edwards, M., M. Davies, and A. Edwards, *What are the external influences on information exchange and shared decision-making in healthcare consultations: a meta-synthesis of the literature.* Patient Education and Counseling, 2009. **75**(1): p. 37-52.
16. Renahy, E. and P. Chauvin, *Internet uses for health information seeking: a literature review.* Revue d'épidémiologie et de santé publique, 2006. **54**(3): p. 263-275.
17. Pluye, P., et al. *What are the Outcomes Associated With On-line Consumer Health Information use? A mixed studies systematic review*. in *Family Medicine Forum*. 2014. Quebec City.
18. Lewis, T., *Seeking health information on the internet: lifestyle choice or bad attack of cyberchondria?* Media, Culture & Society, 2006. **28**(4): p. 521-539.
19. White, R.W. and E. Horvitz, *Cyberchondria: studies of the escalation of medical concerns in web search.* ACM Transactions on Information Systems (TOIS), 2009. **27**(4): p. 23.

20. Iverson, S.A., K.B. Howard, and B.K. Penney, *Impact of internet use on health-related behaviors and the patient-physician relationship: a survey-based study and review.* J Am Osteopath Assoc, 2008. **108**(12): p. 699-711.
21. Ahmad, F., et al., *Are physicians ready for patients with Internet-based health information?* Journal of Medical Internet Research, 2006. **8**(3).
22. Beaudoin, J., *Génération @: Portrait de l'utilisation d'Internet et de l'ordinateur par les aînés internautes du Québec.* Canadian Electronic Library (Firm), Centre francophone d'informatisation des organisations., CEFRIO, 2011.
23. Cline, R.J. and K.M. Haynes, *Consumer health information seeking on the Internet: the state of the art.* Health education research, 2001. **16**(6): p. 671-692.
24. Pereira, J. and E. Bruera, *The Internet as a Resource for Palliative Care and Hospice.* Journal of Pain and Symptom Management. **16**(1): p. 59-68.
25. Fox, S., *The social life of health information 2011*. 2011: Pew Internet & American Life Project Washington, DC.
26. Sillence, E., et al., *How do patients evaluate and make use of online health information?* Social science & medicine, 2007. **64**(9): p. 1853-1862.
27. van Uden-Kraan, C.F., et al., *Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia.* Qualitative Health Research, 2008. **18**(3): p. 405-417.
28. Gabriel, Y., *10: The voice of experience and the voice of the expert–can they speak to each other?* Narrative research in health and illness, 2004: p. 168.
29. Johnston, A.C., et al., *Online health communities: An assessment of the influence of participation on patient empowerment outcomes.* Information Technology & People, 2013. **26**(2): p. 213-235.
30. Jadad, A.R., et al., *Are virtual communities good for our health?* BMJ, 2006. **332**(7547): p. 925-926.
31. Nambisan, P., *Information seeking and social support in online health communities: impact on patients' perceived empathy.* Journal of the American Medical Informatics Association, 2011. **18**(3): p. 298-304.
32. Kloda, L.A. and J.C. Bartlett, *A characterization of clinical questions asked by rehabilitation therapists.* Journal of the Medical Library Association: JMLA, 2014. **102**(2): p. 69.
33. Schattner, A., *The clinical encounter revisited.* The American journal of medicine, 2014. **127**(4): p. 268-274.
34. Roter, D., *The enduring and evolving nature of the patient–physician relationship.* Patient education and counseling, 2000. **39**(1): p. 5-15.
35. Hart, A., F. Henwood, and S. Wyatt, *The role of the Internet in patient-practitioner relationships: findings from a qualitative research study.* Journal of Medical Internet Research, 2004. **6**(3).
36. Donnelly, L.S., R.L. Shaw, and O.B. van den Akker, *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, 2008. **101**(10): p. 501-506.
37. Pluye, P., et al., *What are the outcomes of the use of online consumer health information? A participatory systematic mixed studies review*, in *North American Primary Care Group*. 2015: Cancun, Mexico.
38. El Sherif, R., et al., *Performance of a mixed filter to identify relevant studies for mixed studies reviews.* Journal of the Medical Library Association: JMLA, 2016. **104**(1): p. 47.
39. Pluye, P. and Q.N. Hong, *Combining the Power of Stories and the Power of Numbers: Mixed Methods Research and Mixed Studies Reviews.* Annual review of public health, 2013(0).
40. Whittemore, R. and K. Knafl, *The integrative review: updated methodology.* Journal of advanced nursing, 2005. **52**(5): p. 546-553.

41. Fereday, J. and E. Muir-Cochrane, *Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development.* International journal of qualitative methods, 2008. **5**(1): p. 80-92.
42. Flocke, S.A., L.E. Gordon, and G.L. Pomiecko, *Evaluation of a community health promotion resource for primary care practices.* American journal of preventive medicine, 2006. **30**(3): p. 243-251.
43. Goldschmidt, L. and G.L. Goodrich, *Development and evaluation of a point-of-care interactive patient education kiosk.* Journal of telemedicine and telecare, 2004. **10**(suppl 1): p. 30-32.
44. Popay, J., et al., *Guidance on the conduct of narrative synthesis in systematic reviews.* ESRC methods programme, 2006. **15**(1): p. 047-71.
45. Saracevic, T. and P.B. Kantor, *Studying the value of library and information services. Part I. Establishing a theoretical framework.* Journal of the American Society for Information Science, 1997. **48**(6): p. 527-542.
46. Bianco, A., et al., *Parents seeking health-related information on the Internet: cross-sectional study.* Journal of medical Internet research, 2013. **15**(9).
47. Houston, T.K. and J.J. Allison, *Users of Internet health information: differences by health status.* Journal of medical Internet research, 2002. **4**(2).
48. Laflamme, D.J., *Online health information-seeking, health locus of control and health literacy among low-income Internet users in east Baltimore*. 2003, The Johns Hopkins University.
49. Caiata-Zufferey, M., et al., *Online health information seeking in the context of the medical consultation in Switzerland.* Qualitative Health Research, 2010. **20**(8): p. 1050-1061.
50. Powell, J., et al., *The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study.* Journal of Medical Internet Research, 2011. **13**(1).
51. Lev, E., *Googling While Expecting: Internet Use by Israeli Women during Pregnancy*. 2009, Ohio University.
52. Lagan, B.M., M. Sinclair, and W.G. Kernohan, *What Is the Impact of the Internet on Decision-Making in Pregnancy? A Global Study.* Birth, 2011. **38**(4): p. 336-345.
53. Macias, W. and S. McMillan, *The return of the house call: the role of Internet-based interactivity in bringing health information home to older adults.* Health Communication, 2008. **23**(1): p. 34-44.
54. Sommerhalder, K., et al., *Internet information and medical consultations: experiences from patients' and physicians' perspectives.* Patient education and counseling, 2009. **77**(2): p. 266-271.
55. Kim, J. and S. Kim, *Physicians' perception of the effects of Internet health information on the doctor-patient relationship.* Informatics for Health & Social Care, 2009. **34**(3): p. 136-148.
56. Berg, K.A., *Health Management in the Age of the Internet*. 2011, University of Toronto.
57. Amirault, M., et al., *Consumer health information on the Internet: an evaluation report on the Nova Scotia Health Network.* Journal of the Canadian Health Libraries Association/Journal de l'Association des bibliothèques de la santé du Canada, 2005. **26**(2): p. 41-46.
58. Anderson, J.G., *Consumers of e-health patterns of use and barriers.* Social Science Computer Review, 2004. **22**(2): p. 242-248.
59. Bansil, P., et al., *PEER REVIEWED: Health-related Information on the Web: Results From the HealthStyles Survey, 2002–2003.* Preventing chronic disease, 2006. **3**(2).
60. Chung, J.E., *Patient–provider discussion of online health information: results from the 2007 Health Information National Trends Survey (HINTS).* Journal of health communication, 2013. **18**(6): p. 627-648.

61. Dolan, G., et al., *Consumer use of the internet for health information: a survey of primary care patients.* International Journal of Consumer Studies, 2004. **28**(2): p. 147-153.
62. Bylund, C.L., et al., *Provider–patient dialogue about Internet health information: an exploration of strategies to improve the provider–patient relationship.* Patient education and counseling, 2007. **66**(3): p. 346-352.
63. Baker, L., et al., *Use of the Internet and e-mail for health care information: results from a national survey.* Jama, 2003. **289**(18): p. 2400-2406.
64. Cohall, A.T., et al., *Computer use, internet access, and online health searching among Harlem adults.* American Journal of Health Promotion, 2011. **25**(5): p. 325-333.
65. Pena-Purcell, N., *Hispanics' use of Internet health information: an exploratory study.* Journal of the Medical Library Association, 2008. **96**(2): p. 101-7.
66. Coberly, E., et al., *Linking clinic patients to Internet-based, condition-specific information prescriptions.* Journal of the Medical Library Association: JMLA, 2010. **98**(2): p. 160.
67. Siegel, E.R., et al., *Information Rx: evaluation of a new informatics tool for physicians, patients, and libraries.* Information Services and Use, 2006. **26**(1): p. 1-10.
68. Nicholas, D., et al., *Digital health information provision and health outcomes.* Journal of Information Science, 2001. **27**(4): p. 265-276.
69. Couper, M.P., et al., *Use of the Internet and ratings of information sources for medical decisions: results from the DECISIONS survey.* Medical Decision Making, 2010. **30**(5 suppl): p. 106S-114S.
70. Kavathe, R., *Patterns of access and use of online health information among Internet users: A case study*. 2009, Bowling Green State University.
71. Pifalo, V., et al., *The impact of consumer health information provided by libraries: the Delaware experience.* Bulletin of the Medical Library Association, 1997. **85**(1): p. 16.
72. Mayoh, J., L. Todres, and C.S. Bond, *Exploring the online health information seeking experiences of older adults.* Indo-Pacific Journal of Phenomenology, 2013. **11**(2).
73. Walsh, A.M., et al., *Predictive modelling: parents' decision making to use online child health information to increase their understanding and/or diagnose or treat their child's health.* BMC medical informatics and decision making, 2012. **12**(1): p. 144.
74. Kivits, J., *Informed patients and the internet: a mediated context for consultations with health professionals.* Journal of Health Psychology, 2006. **11**(2): p. 269-82.
75. Beck, F., et al., *Use of the internet as a health information resource among French young adults: results from a nationally representative survey.* Journal of medical Internet research, 2014. **16**(5).
76. Ayers, S.L. and J.J. Kronenfeld, *Chronic illness and health-seeking information on the Internet.* Health:, 2007. **11**(3): p. 327-347.
77. Takahashi, Y., et al., *Internet Use for Health-Related Information via Personal Computers and Cell Phones in Japan: A Cross-Sectional Population-Based Survey.* Journal of Medical Internet Research, 2011. **13**(4).
78. Weaver, J.B., et al., *Healthcare non-adherence decisions and internet health information.* Computers in Human Behavior, 2009. **25**(6): p. 1373-1380.
79. Entwistle, V.A., et al., *Evidence-informed patient choice: practical issues of involving patients in decisions about health care technologies.* International Journal of Technology Assessment in Health Care, 1998. **14**(02): p. 212-225.
80. Cohall, A.T., et al., *Computer use, internet access, and online health searching among Harlem adults.* American Journal of Health Promotion, 2011. **25**(5): p. 325-33.
81. Kavathe, R., *Patterns of access and use of online health information among Internet users: A case study.* Dissertation Abstracts International Section A: Humanities and Social Sciences, 2010. **70**(9-A): p. 3278.

82. Laflamme, D.J., *Online health information-seeking, health locus of control and health literacy among low-income internet users in east baltimore.* Dissertation Abstracts International: Section B: The Sciences and Engineering, 2003. **64**(2-B): p. 666.
83. Rice, R.E., *Influences, usage, and outcomes of Internet health information searching: multivariate results from the Pew surveys.* International Journal of Medical Informatics, 2006. **75**(1): p. 8-28.
84. Iverson, S.A., K.B. Howard, and B.K. Penney, *Impact of internet use on health-related behaviors and the patient-physician relationship: a survey-based study and review.* Journal of the American Osteopathic Association, 2008. **108**(12): p. 699-711.
85. Powell, J., et al., *The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study.* Journal of Medical Internet Research, 2011. **13**(1): p. e20.
86. Ybarra, M. and M. Suman, *Reasons, assessments and actions taken: sex and age differences in uses of Internet health information.* Health Education Research, 2008. **23**(3): p. 512-21.
87. Murray, E., et al., *The impact of health information on the internet on the physician-patient relationship: patient perceptions.* Archives of Internal Medicine, 2003. **163**(14): p. 1727-34.
88. Liszka, H.A., T.E. Steyer, and W.J. Hueston, *Virtual medical care: how are our patients using online health information?* Journal of community health, 2006. **31**(5): p. 368-378.
89. Bujnowska-Fedak, M.M., A. Staniszewski, and A. Steciwko, *A survey of Internet use for health purposes in Poland.* Journal of Telemedicine and Telecare, 2007. **13**(suppl 1): p. 16-19.
90. Coberly, E., et al., *Linking clinic patients to Internet-based, condition-specific information prescriptions.* Journal of the Medical Library Association, 2010. **98**(2): p. 160-4.
91. Hitchcock, P.B. and A. Mathews, *Interpretation of bodily symptoms in hypochondriasis.* Behaviour Research and Therapy, 1992. **30**(3): p. 223-234.
92. Coates, R., M.D. Sykora, and T. Jackson, *An investigation of Cyberchondria in 'The Age of Risk'.* 2015.
93. Hart, A., F. Henwood, and S. Wyatt, *The role of the Internet in patient-practitioner relationships: findings from a qualitative research study.* Journal of medical Internet research, 2004. **6**(3): p. e36.
94. Burton-Jeangros, C. and R. Hammer, *Recherche d'informations sur internet: quels sont les usages des femmes enceintes?* Revue médicale suisse, 2013(9): p. 895-897.
95. Singh, K. and R.J. Brown, *Health-related Internet habits and health anxiety in university students.* Anxiety, Stress & Coping, 2014(ahead-of-print): p. 1-13.
96. Eastin, M.S. and N.M. Guinsler, *Worried and wired: effects of health anxiety on information-seeking and health care utilization behaviors.* CyberPsychology & Behavior, 2006. **9**(4): p. 494-498.
97. Rogers, A. and N. Mead, *More than technology and access: primary care patients' views on the use and non-use of health information in the Internet age.* Health & social care in the community, 2004. **12**(2): p. 102-110.
98. Murray, E., et al., *The impact of health information on the internet on the physician-patient relationship: patient perceptions.* Archives of Internal Medicine, 2003. **163**(14): p. 1727-1734.
99. Saracevic, T. and P. Kantor, *Studying the value of library and information services. Part 1. Establishing a theoretical framework.* J Am Soc Inf Sci Technol, 1997. **48**(6): p. 527-542.
100. Pluye, P., et al., *Four levels of outcomes of information-seeking: A mixed methods study in primary health care.* J Am Soc Inf Sci Technol, 2013. **64**(1): p. 108–125.
101. Pluye, P., et al., *Development and Content Validation of the Information Assessment Method for Patients and Consumers.* J Med Internet Res, 2014. **3**(1): p. e7.

102. Savolainen, R., *Network competence and information seeking on the Internet: From definitions towards a social cognitive model.* Journal of documentation, 2002. **58**(2): p. 211-226.
103. Dervin, B., *Human studies and user studies: a call for methodological inter-disciplinarity.* Information Research, 2003. **9**(1).
104. Reijo Savolainen, *Information Behavior and Information Practice: Reviewing the "Umbrella Concepts" of Information-Seeking Studies.* The Library Quarterly: Information, Community, Policy, 2007. **77**(2): p. 109-132.
105. Wilson, T.D., *Revisiting user studies and information needs.* Journal of documentation, 2006. **62**(6): p. 680-684.
106. Fisher, K.E., C.F. Landry, and C. Naumer, *Social spaces, casual interactions, meaningful exchanges:'information ground'characteristics based on the college student experience.* Information Research, 2006. **12**(2): p. 3.
107. Courtright, C., *Context in information behavior research.* Annual review of information science and technology, 2007. **41**(1): p. 273-306.
108. Loiselle, C.G., S.D. Lambert, and S. Dubois, *Beyond the mere dichotomy of active search versus avoidance of information about the self.* Journal of the Medical Library Association, 2006. **94**(4): p. 375.
109. Santana, S., et al., *Informed citizen and empowered citizen in health: results from an European survey.* BMC family practice, 2011. **12**(1): p. 20.
110. Kindig, D.A., A.M. Panzer, and L. Nielsen-Bohlman, *Health Literacy:: A Prescription to End Confusion*. 2004: National Academies Press.
111. Murray, T., et al., *Health literacy in Canada: a healthy understanding 2008.* Ottawa (ON): Canadian Council on Learning, 2008.
112. Xie, B. and J.M. Bugg, *Public library computer training for older adults to access high-quality Internet health information.* Library & Information Science Research, 2009. **31**(3): p. 155-162.
113. Street, R.L., *How clinician–patient communication contributes to health improvement: modeling pathways from talk to outcome.* Patient education and counseling, 2013. **92**(3): p. 286-291.
114. Sandelowski, M., *Focus on research methods-whatever happened to qualitative description?* Research in nursing and health, 2000. **23**(4): p. 334-340.
115. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* International Journal for Quality in Health Care, 2007. **19**(6): p. 349-357.
116. Merolli, M., F.J.M. Sanchez, and K. Gary, *Social Media and Online Survey: Tools for Knowledge Management in Health Research.* 2014.
117. Patton, M.Q., *Qualitative research*. 2005: Wiley Online Library.
118. Cachia, M. and L. Millward, *The telephone medium and semi-structured interviews: a complementary fit.* Qualitative Research in Organizations and Management: An International Journal, 2011. **6**(3): p. 265-277.
119. Sturges, J.E. and K.J. Hanrahan, *Comparing telephone and face-to-face qualitative interviewing: a research note.* Qualitative Research, 2004. **4**(1): p. 107-118.
120. Burke, L.A. and M.K. Miller, *Phone Interviewing as a Means of Data Collection: Lessons Learned and Practical Recommendations.* 2001, 2001. **2**(2).
121. Whiting, L.S., *Semi-structured interviews: guidance for novice researchers.* Nursing Standard, 2008. **22**(23): p. 35-40.
122. Kaiser, K., *Protecting Respondent Confidentiality in Qualitative Research.* Qualitative health research, 2009. **19**(11): p. 1632-1641.
123. Sandelowski, M., *Sample size in qualitative research.* Research in nursing & health, 1995. **18**(2): p. 179-183.

124. Clarke, V. and V. Braun, *Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning.* The psychologist, 2013. **26**(2): p. 120-123.
125. Sandelowski, M., *Telling stories: Narrative approaches in qualitative research.* Image: the journal of nursing scholarship, 1991. **23**(3): p. 161-166.
126. McCormack, C., *From interview transcript to interpretive story: Part 1—Viewing the transcript through multiple lenses.* Field Methods, 2000. **12**(4): p. 282-297.
127. Medlock, S., et al., *Health information–seeking behavior of seniors who use the internet: a survey.* Journal of medical Internet research, 2015. **17**(1): p. e10.
128. Hesse , B.W., R.P. Moser , and L.J. Rutten *Surveys of Physicians and Electronic Health Information.* New England Journal of Medicine, 2010. **362**(9): p. 859-860.
129. Librarianship, A., *The librarian's role in the provision of consumer health information and patient education.* Bull Med Libr Assoc, 1996. **84**(2): p. 238.
130. Cohen, D. and B. Crabtree, *Qualitative research guidelines project*. 2006.
131. Nadin, S. and C. Cassell, *The use of a research diary as a tool for reflexive practice: some reflections from management research.* Qualitative Research in Accounting & Management, 2006. **3**(3): p. 208-217.
132. Ortlipp, M., *Keeping and using reflective journals in the qualitative research process.* The qualitative report, 2008. **13**(4): p. 695-705.
133. Ritchie, J., et al., *Qualitative research practice: A guide for social science students and researchers*. 2013: Sage.
134. Fergus, T.A. and S.L. Dolan, *Problematic internet use and internet searches for medical information: the role of health anxiety.* Cyberpsychology, Behavior, and Social Networking, 2014. **17**(12): p. 761-765.
135. Nahl, D. and D. Bilal, *Information and emotion: The emergent affective paradigm in information behavior research and theory*. 2007: Information Today, Inc.
136. Fahy, E., et al., *Quality of patient health information on the Internet: reviewing a complex and evolving landscape.* The Australasian medical journal, 2013. **7**(1): p. 24-28.
137. van Uden-Kraan, C.F., et al., *Experiences and attitudes of Dutch rheumatologists and oncologists with regard to their patients' health-related Internet use.* Clinical rheumatology, 2010. **29**(11): p. 1229-1236.
138. Agius, M. and H. Stangeland, *How Does the Internet Influence the Doctor–Patient Relationship?*, in *e-Mental Health*. 2016, Springer. p. 251-267.
139. Norr, A.M., D.W. Capron, and N.B. Schmidt, *Medical information seeking: Impact on risk for anxiety psychopathology.* Journal of Behavior Therapy and Experimental Psychiatry, 2014. **45**(3): p. 402-407.
140. Hewitt-Taylor, J. and C.S. Bond, *What e-patients want from the doctor-patient relationship: content analysis of posts on discussion boards.* Journal of medical Internet research, 2012. **14**(6): p. e155.
141. Jacob, J., *Consumer access to health care information: its effect on the physician-patient relationship.* Alaska medicine, 2001. **44**(4): p. 75-82.
142. Amsellem-Mainguy, Y., *Prescrire et proscrire des conduites, véhiculer des normes: les mères comme actrices privilégiées de prévention en matière de sexualité et de contraception.* Recherches familiales, 2006(1): p. 49-59.
143. Dictionary, M.-W., *Merriam-Webster Dictionary (2014)*. 2014, Retrieved 1/20/2014 from http://www. merriam-webster. com/dictionary/culture.
144. Tanis, M., T. Hartmann, and F. te Poel, *Online health anxiety and consultation satisfaction: A quantitative exploratory study on their relations.* Patient education and counseling, 2016.

145. Anderson, J.G., M.R. Rainey, and G. Eysenbach, *The impact of CyberHealthcare on the physician–patient relationship.* Journal of medical systems, 2003. **27**(1): p. 67-84.
146. Piette, J.D., et al., *The role of patient-physician trust in moderating medication nonadherence due to cost pressures.* Archives of internal medicine, 2005. **165**(15): p. 1749-1755.
147. Wroth, T.H. and D.E. Pathman, *Primary medication adherence in a rural population: the role of the patient-physician relationship and satisfaction with care.* The Journal of the American Board of Family Medicine, 2006. **19**(5): p. 478-486.
148. Schneider, J., et al., *Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection.* Journal of general internal medicine, 2004. **19**(11): p. 1096-1103.
149. Silver, M.P., *Patient perspectives on online health information and communication with doctors: a qualitative study of patients 50 years old and over.* J Med Internet Res, 2015. **17**(1): p. e19.
150. Iacovetto, M.C. and L.A. Allen, *Transitioning into a digital world: Time for providers to recommend internet health information?* American heart journal, 2015. **170**(1): p. 1-2.
151. Walraven, A., S. Brand-Gruwel, and H.P.A. Boshuizen, *Fostering transfer of websearchers' evaluation skills: A field test of two transfer theories.* Computers in Human Behavior, 2010. **26**(4): p. 716-728.
152. Wiley, J., et al., *Source Evaluation, Comprehension, and Learning in Internet Science Inquiry Tasks.* American Educational Research Journal, 2009. **46**(4): p. 1060-1106.
153. Diviani, N., et al., *Low Health Literacy and Evaluation of Online Health Information: A Systematic Review of the Literature.* Journal of Medical Internet Research, 2015. **17**(5): p. e112.
154. Crouch, M. and H. McKenzie, *The logic of small samples in interview-based qualitative research.* Social science information, 2006. **45**(4): p. 483-499.
155. Pluye, P., et al., *Four levels of outcomes of information-seeking: A mixed methods study in primary health care.* Journal of the American Society for Information Science and Technology, 2013. **64**(1): p. 108-125.
156. Higgins, J. and S. Green, *Cochrane Handbook for Systematic Reviews of Interventions. Version*

5.1.0 The Cochrane Collaboration, 2011.
157. Straus, S.E., J. Tetroe, and I. Graham, *Defining knowledge translation.* Canadian Medical Association Journal, 2009. **181**(3-4): p. 165-168.
158. Pace, R., et al., *Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review.* International journal of nursing studies, 2012. **49**(1): p. 47-53.
159. Crowe, M. and L. Sheppard, *A review of critical appraisal tools show they lack rigor: alternative tool structure is proposed.* Journal of clinical epidemiology, 2011. **64**(1): p. 79-89.
160. Boyatzis, R.E., *Transforming qualitative information: Thematic analysis and code development*. 1998: Sage.

Appendix I. Literature Review

Eligibility criteria

Records were imported in EndNote, and duplicates removed. To identify potentially relevant studies, the list of records was compiled in EndNote and imported into an online specialized software for coding (Distiller SR).[59] For each record, two reviewers independently assigned inclusion codes. For each criterion, there were three response options: I agree, I disagree, and I cannot tell.

Inclusion criteria (codes):

- The record concerns the patients' use of online consumer health information, or patient health outcomes associated with information-use. We will include studies about general information on health and medical topics (for non-programmed decision-making). In contrast, studies on decision support system for programmed decision-making will be excluded.
- The record concerns primary health care: (a) primary health care topics (i.e., health promotion, disease prevention, early detection of a disease, and comorbidities), or (b) primary health care actors (i.e., individuals [self-care], community organizations, and clinicians such as community pharmacists and family physicians), or (c) primary health care services (i.e., first-contact care, care coordination, care over-time, and comprehensive care). In contrast, records concerning secondary health care (e.g., hospitalized patients), or specific disease (e.g., cancer), will be excluded.
- The record concerns a primary empirical research study (i.e., an original qualitative, or quantitative, or mixed methods study). In contrast, records reporting a commentary, an editorial, an essay, a letter, or a review, will be excluded.
- The record concerns a publication written in English or French.

Information sources and search strategy

The search strategy was prepared by three specialized librarians. The strategy is complex for two reasons. Firstly, we cannot use filters for primary health care, as many studies about online consumer health information do not mention primary health care settings or professionals. Secondly, while comments, editorials, letters, and reviews will be excluded, there are no specific filters for retrieving all empirical studies at once (original qualitative, quantitative, and mixed methods studies).

Thus, we combined four strategies for retrieving publications reporting randomized controlled trials, non-randomized studies, descriptive quantitative studies, qualitative research, and mixed methods research. The search filter we created, the 'mixed filter' has since been tested and found to be very reliable[38]

The four main databases were: Medline, Embase, PsycINFO, and Cinahl. Other bibliographic databases (LISA, ERIC, Cochrane Library, Library, Information Science & Technology Abstracts, and British Nursing Index) were searched using a variation or modified version of the Medline search strategy, along with hedges and limits.

Grey Literature: Google Scholar, ProQuest Dissertations and Theses, Theses Canada Portal.

Selection of relevant studies and data collection process

The bibliographic software EndNote was used to store records with indexing terms, and remove duplicates. These records (with only titles and abstracts) were then imported into an online specialized software (Distiller SR). For each record, two independent reviewers assigned codes associated with our eligibility criteria. Any record that did not have an abstract was searched online until an abstract was found or they were excluded. Any discrepancy between reviewers was identified by Distiller and resolved by discussion and usually led to one reviewer changing their code. Disagreements that were not resolved easily were referred to a third party and if still not resolved, were moved to the next step for full-text review.[156]

For the next step, all the 'included' records at the abstract phase were exported into an Endnote library where their full text published articles and research reports were found and attached. They were then once again imported into Distiller SR and two independent reviewers viewed the text and assigned 'eligibility' codes. As with the previous step, disagreements between reviewers were resolved by discussion or through a third party. All included full-text studies were then exported from Distiller into an Excel file and an Endnote library was created with only these included studies.

Appraisal of the quality of selected studies

Critical appraisal is a core component of systematic reviews [157]; we assessed the methodological quality of included studies using the Mixed Methods Appraisal Tool (MMAT). The purpose of the MMAT is to concomitantly appraise qualitative, quantitative, and mixed methods studies for Systematic Mixed Studies Reviews. The 2011 version of the MMAT was used.[158] The MMAT is considered a unique validated critical appraisal tool for all types of designs, including mixed methods research.[159]

Using the MMAT appraisal form, two independent reviewers appraised the included studies using Distiller where the items from the MMAT were used as questions. Disagreements between reviewers was resolved in the same manner as the selection process, first by discussion between the reviewers then by a third party.

Thematic synthesis of included studies

We conducted a qualitative thematic analysis using an hybrid inductive-deductive approach (assigning study results to pre-defined themes, and creating new themes as needed) [41]. All included studies were imported into an NVivo project that was shared between two researchers (myself and an assistant). The themes from our framework were created as 'thematic nodes' into the project, and 'descriptive' nodes were also created to allow us to describe the study. The studies were randomly divided between the two of us and we each independently coded the text to the existing nodes/themes, and created new nodes/themes as needed. A detailed research diary was maintained by each researcher to explain any new theme that was created and provide justification for its creation. Consistency and rigour in our qualitative synthesis were based on an interpretative method and research meetings.[160] A meeting was held following the completion of the first ten studies and we discussed all our concerns and any new themes that were derived until we agreed on them. A bi-monthly meeting was then held until all the studies were coded. For the purpose of my thesis I specifically focused on negative outcomes and re-analyzed all the data coded under the theme specified for negative outcomes. It is studies that mentioned a negative outcome specifically that I have summarized below.

Figure 4 PRISMA flow diagram

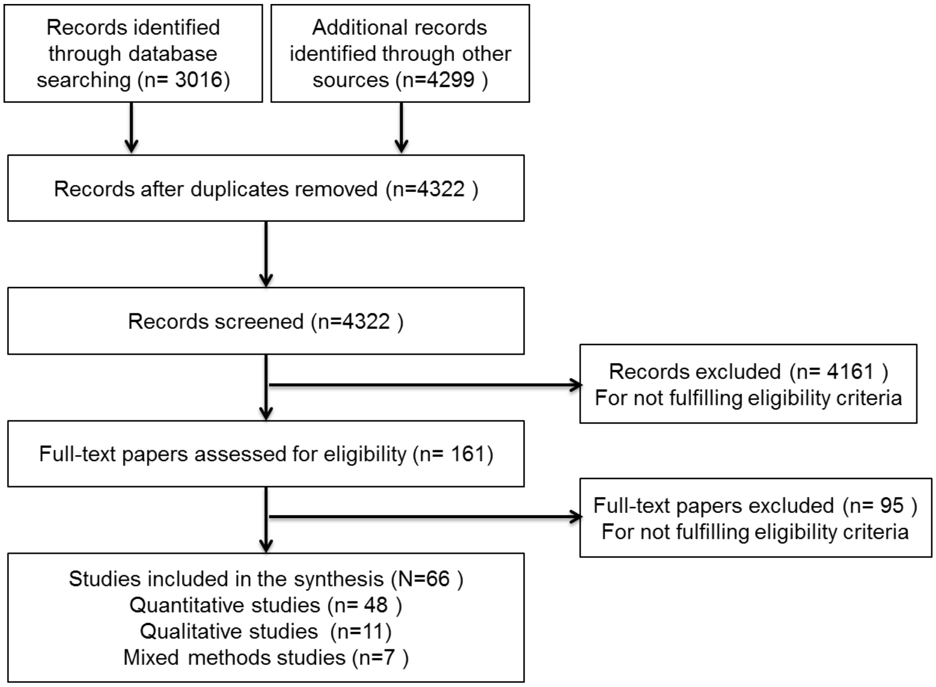


Table 9 Description of Included Studies in Literature Review

First author, year	Study description	Type of negative patient health outcome
Ahmad et al. (2006)	Six focus groups were conducted with 48 family physicians practising in Toronto. The data were analyzed using qualitative methods of content analysis and constant comparison, derived from grounded theory approach.	Physicians in this study generally perceived Internet based health information as problematic when introduced by patients during medical consultations. They believed that Internet information often generated patient misinformation, leading to confusion, distress, or an inclination towards detrimental self-diagnosis and/or self-treatment. Physicians felt these influences added a new interpretive role to their clinical responsibilities.
Berg 2011	Sequential mixed methods design. East York, Toronto: 350 people surveyed, 87 interviewed.	One interviewee's fears about exposure to Internet based information sounds like a version of "cyberchondria" one of the warned against responses to online health information where exposure to information changes your relationship with health in a negative fashion
Bianco 2013	This cross-sectional study was conducted from April to June 2012. The sample consisted of 1544 adults aged ≥18 years selected among parents of public school students in the geographic area of Catanzaro in southern Italy. A total of 1039 parents completed the questionnaire.	A total of 8.1% (60/740) believed it had a negative effect on their relationship with their GP.
Bujnowska-Fedak et al. (2007)	A telephone survey was performed of 1027 people between 15 and 80 years old who were selected from the Polish population by random sampling.	25% of participants reported that finding OCHI increased their anxiety.
Burton-Jeangros & Hammer (2013)	Qualitative. The study, conducted in French speaking Switzerland between 2008 and 2009, was performed by semi-structured interviews with 50 pregnant women aged 24-41 years.	Anxiety over the risks mentioned in the information
Caiata-Zufferey et al (2010)	Qualitative. Semi-structured interviews with patients who searched for health information online before or after a medical consultation Italian part of Switzerland between 2005 and 2007. 27 patients recruited in the waiting room of 14 medical practices	Gaps or discrepancies in patients' knowledge systems created or enhanced a sense of uncertainty of their situation, left them disoriented and powerless, unable to decide how to act and to project themselves in the future.
Chung (2013)	Quantitative descriptive. This study used data from the 2007 Health Information National Trends Survey (HINTS), developed by the National Cancer Institute (n = 5,078 internet users). .	Reactions of HCPs to online information were perceived as particularly negative by certain groups of patients, such as those who experienced poor health and those who had more concerns about the quality of their searched information.
	Quantitative cross-sectional survey. Participants were emailed and invited to complete an online	The results suggest that individuals with even moderate levels of anxiety seek higher amounts of online health information. Frequent

Eastin and Guinsler, 2006.	survey about how people used the Internet for different reasons; a total response rate of 24% was obtained.	online seekers also tend to make more medical appointments based on information found online. (Moreover, this study found a negative relationship between searching for health information online and visiting a doctor based on that information for individuals at the lower end of the health-anxiety spectrum.)
Hart et al (2004)	Qualitative interviews and observations of patient–practitioner interaction, purposive sample of 47 patients (32 women and 15 men)	Patients reported that some health practitioners sought to assert their authority by dismissing the patient's acquired knowledge. For example, one woman said some health practitioners had made it clear that they thought she should not look things up for herself. She felt that the view was, “you're here with me now and I'm telling you this” The Internet's role in feeding the anxieties of patients with hypochondria was raised by three practitioners, and problems with “all sorts of odd Web sites,” and patients coming in armed with printouts were mentioned by a further two
Iverson et al (2008)	Quant descriptive. A standardized eight-question survey regarding Internet use and healthcare was given to patients at three osteopathic primary care medical clinics. N=154	A related concern commonly voiced by physicians regarding the influence of the Internet on the patient-physician relationship is that, on the basis of inaccurate, inadequate, or misleading online information, patients may begin a self-treatment regimen that is ineffective or potentially hazardous. Indeed, some patients may attempt to use online information for self-diagnosis and self-treatment when they are unable to obtain an appointment with their physicians quickly.
Kim and Kim, (2009)	Quantitative cross-sectional survey. Online questionnaire with 25 items were sent to the Korean physicians' e-mails, to determine physician's perception of the effects of health information on the internet on doctor–patient relationship and 493 replied.	Respondents felt that the patients who obtained Internet health information has a lower tendency to comply with the physician's instructions or advice, have unnecessary fears or concerns about their health and that Internet health information contributes to increase in health care cost as well as causing longer and unnecessary visits.
Kivits (2006)	Qualitative interviews were conducted by email with 31 health information seekers.	'My relationship with dentists has definitely deteriorated. The dentists I know in general practise don’t try to keep up with research and are patronising and arrogant.' Two interviewees who admit sometimes contesting doctors’ diagnoses or treatments after acquiring information gathered on the Internet.
Lagan et al (2011)	Qualitative. 13 asynchronous online focus group discussions across five countries were conducted over a 3-month period. n=92 Participants were drawn from a population of 193 women who had participated in a web-based survey, used the Internet as a medium for	The women in this study mainly viewed the Internet as a positive resource, it did come under some criticism. It was blamed for ‘‘scare mongering,’’

	information in pregnancy, and expressed a willingness to engage in an online focus group	
Lev 2009	"Qualitative interviews with 50 pregnant Israeli women who were medically considered to have a normal pregnancy, were having one fetus, and utilized the internet during their pregnancy	Twelve women talked about receiving a negative reaction, when the internet was mentioned during a visit with their physician. That reaction resulted in their avoiding the issue during subsequent visits with their doctor. The internet is perceived by the women as something that could threaten the power status of the physician and, therefore, put the physician in an uncomfortable position.
Macias & McMillan (2008)	Qualitative. 4 focus groups in different cities of n=31 participants 60 years and older who use the Internet for more than just e-mail	But for many participants who had taken online information to the doctor, the experience was negative. They did not necessarily see the doctors as being averse to technology— just to the individual's attempt to use technology without doctor's supervision. Among those who were hesitant about using the Web prior to a doctor's visit, their concerns were often framed in terms of misdiagnosis.
Murray et al (2003)	"Quant descriptive. Telephone survey of nationally representative sample of the American public, with oversample of people in poor health. N=3209	If the physician was perceived as being threatened by the patient bringing information in, 49% of patients evinced serious dissatisfaction as defined above. Other important predictors of seeking a second opinion or changing health care provider or plan were feeling hurried during the consultation, or rating the physician's communication skills as only fair or poor. 12% of the 256 respondents who brought information to their physician sought a second opinion from an-other physician, 4% changed their physician, and 1% changed their health plan. Only 6% of patients reported negative feelings, such as embarrassment as a result of taking information to their physician, but 15% had felt hurried during the consultation.
Pena-Purcell, (2008)	Quantitative non- Randomized Study (cross-sectional analytic survey). A nationally representative sample of 3,269 adults over 18 were interviewed on their searches for online health information by phone using a structured questionnaire.	Some patients reported -worsening of the physician-patient relationship after online health information was used in the visit
Pifalo et al., (1997)	A questionnaire was mailed to a convenience sample of 270 adults who received information from a Consumer Health Library (intervention) exploring the effects of the information (from Internet and databases) on their decisions, actions, anxiety, and doctor-patient communication	9.8% of the respondents mentioned that increased anxiety was one of the effects of this use.
Powell et al	"Mixed methods. We undertook an online questionnaire survey, offered to users of the NHS	Misuse of accurate information, leading to inappropriate self-

(2011)	Direct website (n=796). A subsample of survey respondents participated in in-depth, semi structured, qualitative interviews by telephone or instant messaging/email (n=26).	diagnosis:
Rogers & Mead (2004)	"Qualitative. Interviews and observations of a sample who had used a free primary-care-based Internet service (n = 5) and interviews with a sample drawn from a survey of patient attitudes to using the Internet for health information (n = 12). Semi-structured interviews were undertaken with five out of the nine inner-city practice patients who used the Internet clinic.	At its worst, information was anxiety-inducing as it was seen as a source of interference both with established ways of coping and with the efforts of experts working in hard- pressed services.
Siegel et al (2006)	Quant descriptive and non-randomized. Results from two comprehensive evaluation studies of the Information Prescription (or “Information Rx”) Program implementation conducted from 2002-05 by the American College of Physicians Foundation (ACPF) and the U.S. National Library of Medicine (NLM). n=907	Interestingly, an equal proportion of reporting physicians expressed concern that additional information could increase anxiety for some patients.
Singh and Brown, 2014.	Quantitative cross-sectional survey Responses on a purpose-made Internet use questionnaire were correlated with health anxiety scores	Health anxiety positively correlated with: frequency of health-related searching, proportion of health related information sought, and time spent online for health purposes, and number of searches for both illness and wellness information. Health anxiety further positively correlated with advantages perceived in health-related Internet use, heightened tension and relief post-search, and perceived doctor disadvantages, yet a greater likelihood to visit a doctor post-search.
Takahashi et al (2011)	"Quant descriptive. We conducted a cross-sectional survey of a quasi-representative sample (N = 1200) of the Japanese general population aged 15–79 years in September 2007.	Small percentage reported increased anxiety after online health information.

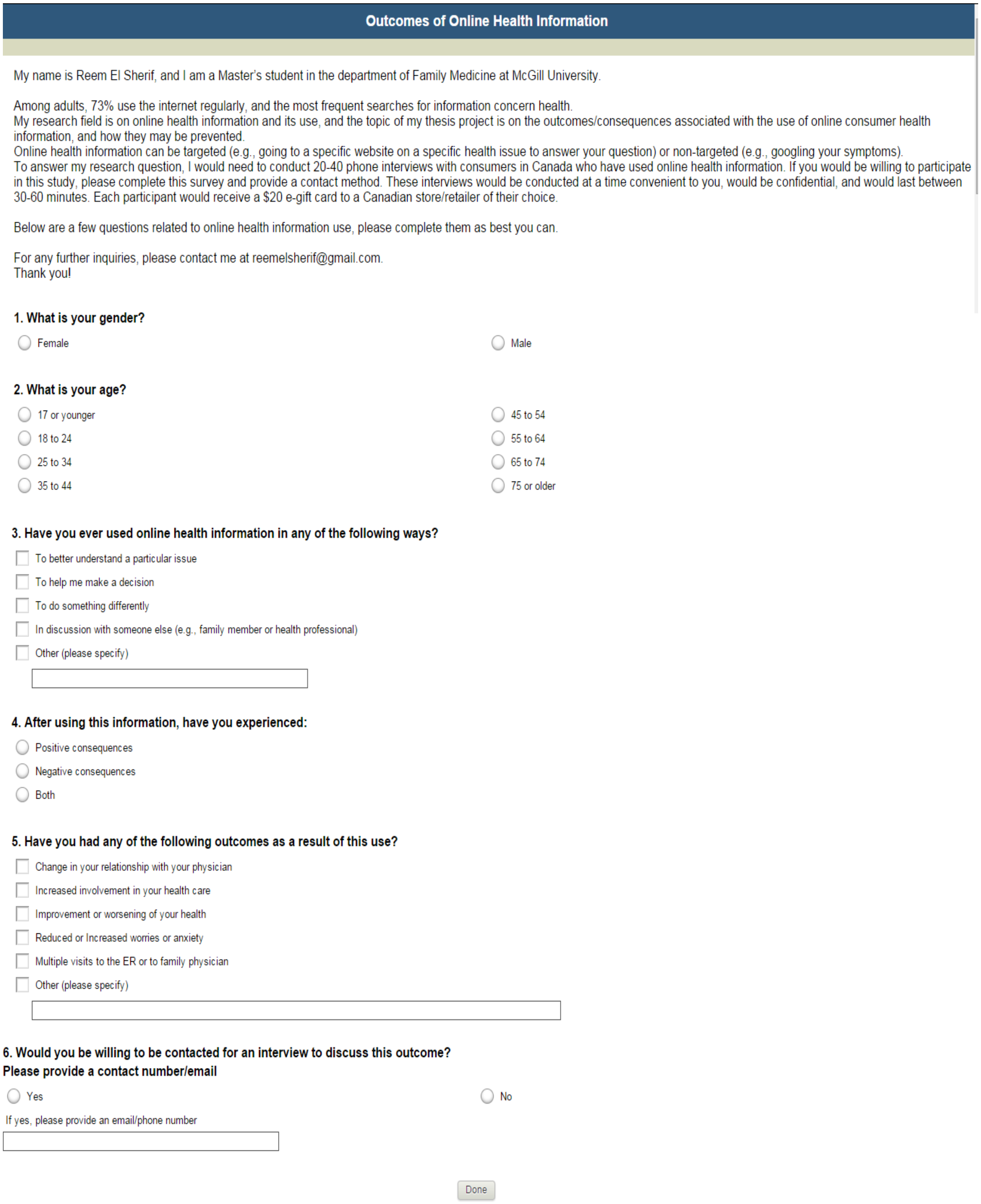
Included Studies

1. Ahmad, F., et al., Are physicians ready for patients with Internet-based health information? Journal of Medical Internet Research, 2006. 8(3).
2. Berg, K.A., Health Management in the Age of the Internet. 2011, University of Toronto.
3. Bianco, A., et al., Parents seeking health-related information on the Internet: cross-sectional study. Journal of medical Internet research, 2013. 15(9).
4. Bujnowska-Fedak, M.M., A. Staniszewski, and A. Steciwko, A survey of Internet use for health purposes in Poland. Journal of Telemedicine and Telecare, 2007. 13(suppl 1): p. 16-19.
5. Burton-Jeangros, C. and R. Hammer, Recherche d’informations sur internet: quels sont les usages des femmes enceintes? Revue médicale suisse, 2013(9): p. 895-897.
6. Caiata-Zufferey, M., et al., Online health information seeking in the context of the medical consultation in Switzerland. Qualitative Health Research, 2010. 20(8): p. 1050-1061.
7. Chung, J.E., Patient–provider discussion of online health information: results from the 2007 Health Information National Trends Survey (HINTS). Journal of health communication, 2013. 18(6): p. 627-648.

8. Eastin, M.S. and N.M. Guinsler, Worried and wired: effects of health anxiety on information-seeking and health care utilization behaviors. CyberPsychology & Behavior, 2006. 9(4): p. 494-498.
9. Hart, A., F. Henwood, and S. Wyatt, The role of the Internet in patient-practitioner relationships: findings from a qualitative research study. Journal of medical Internet research, 2004. 6(3): p. e36.
10. Iverson, S.A., K.B. Howard, and B.K. Penney, Impact of internet use on health-related behaviors and the patient-physician relationship: a survey-based study and review. J Am Osteopath Assoc, 2008. 108(12): p. 699-711.
11. Kim, J. and S. Kim, Physicians' perception of the effects of Internet health information on the doctor-patient relationship. Informatics for Health & Social Care, 2009. 34(3): p. 136-148.
12. Kivits, J., Informed patients and the internet: a mediated context for consultations with health professionals. Journal of Health Psychology, 2006. 11(2): p. 269-82.
13. Lagan, B.M., M. Sinclair, and W.G. Kernohan, What Is the Impact of the Internet on Decision-Making in Pregnancy? A Global Study. Birth, 2011. 38(4): p. 336-345.
14. Lev, E., Googling While Expecting: Internet Use by Israeli Women during Pregnancy. 2009, Ohio University.
15. Macias, W. and S. McMillan, The return of the house call: the role of Internet-based interactivity in bringing health information home to older adults. Health Communication, 2008. 23(1): p. 34-44.
16. Murray, E., et al., The impact of health information on the internet on the physician-patient relationship: patient perceptions. Archives of Internal Medicine, 2003. 163(14): p. 1727-1734.
17. Pena-Purcell, N., Hispanics' use of Internet health information: an exploratory study. Journal of the Medical Library Association, 2008. 96(2): p. 101-7.
18. Pifalo, V., et al., The impact of consumer health information provided by libraries: the Delaware experience. Bulletin of the Medical Library Association, 1997. 85(1): p. 16.
19. Powell, J., et al., The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study. Journal of Medical Internet Research, 2011. 13(1).
20. Rogers, A. and N. Mead, More than technology and access: primary care patients’ views on the use and non-use of health information in the Internet age. Health & social care in the community, 2004. 12(2): p. 102-110.
21. Siegel, E.R., et al., Information Rx: evaluation of a new informatics tool for physicians, patients, and libraries. Information Services and Use, 2006. 26(1): p. 1-10.
22. Singh, K. and R.J. Brown, Health-related Internet habits and health anxiety in university students. Anxiety, Stress & Coping, 2014(ahead-of-print): p. 1-13.
23. Takahashi, Y., et al., Internet use for health-related information via personal computers and cell phones in Japan: a cross-sectional population-based survey. Journal of medical Internet research, 2011. 13(4).

Appendix II. Recruitment Survey and Invitation Letters

Figure 5. Survey used as a recruitment tool



Outcomes of Online Health Information

My name is Reem El Sherif, and I am a Master's student in the department of Family Medicine at McGill University.

Among adults, 73% use the internet regularly, and the most frequent searches for information concern health.
My research field is on online health information and its use, and the topic of my thesis project is on the outcomes/consequences associated with the use of online consumer health information, and how they may be prevented.
Online health information can be targeted (e.g., going to a specific website on a specific health issue to answer your question) or non-targeted (e.g., googling your symptoms).
To answer my research question, I would need to conduct 20-40 phone interviews with consumers in Canada who have used online health information. If you would be willing to participate in this study, please complete this survey and provide a contact method. These interviews would be conducted at a time convenient to you, would be confidential, and would last between 30-60 minutes. Each participant would receive a $20 e-gift card to a Canadian store/retailer of their choice.

Below are a few questions related to online health information use, please complete them as best you can.

For any further inquiries, please contact me at reemelsherif@gmail.com.
Thank you!

1. What is your gender?

○ Female
○ Male

2. What is your age?

○ 17 or younger
○ 18 to 24
○ 25 to 34
○ 35 to 44
○ 45 to 54
○ 55 to 64
○ 65 to 74
○ 75 or older

3. Have you ever used online health information in any of the following ways?

☐ To better understand a particular issue
☐ To help me make a decision
☐ To do something differently
☐ In discussion with someone else (e.g., family member or health professional)
☐ Other (please specify)

4. After using this information, have you experienced:

○ Positive consequences
○ Negative consequences
○ Both

5. Have you had any of the following outcomes as a result of this use?

☐ Change in your relationship with your physician
☐ Increased involvement in your health care
☐ Improvement or worsening of your health
☐ Reduced or Increased worries or anxiety
☐ Multiple visits to the ER or to family physician
☐ Other (please specify)

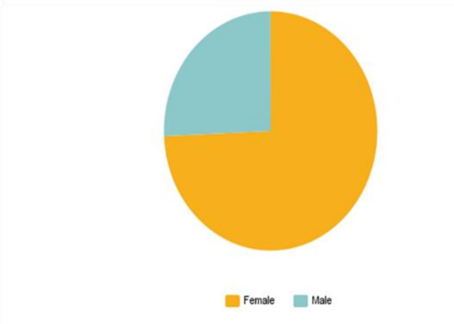
6. Would you be willing to be contacted for an interview to discuss this outcome?
Please provide a contact number/email

○ Yes
○ No

If yes, please provide an email/phone number

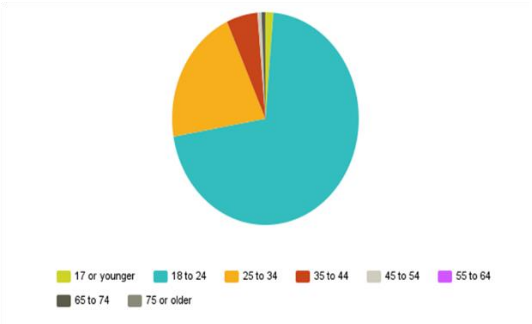
Q1: What is your gender?

Answered: 148 Skipped: 0



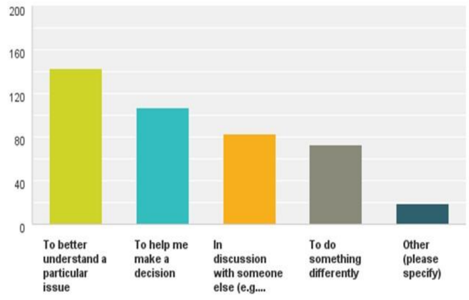
Q2: What is your age?

Answered: 148 Skipped: 0



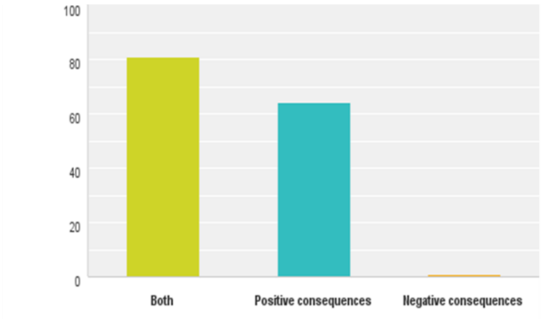
Q3: Have you ever used online health information in any of the following ways?

Answered: 148 Skipped: 0



Q4: After using this information, have you experienced:

Answered: 146 Skipped: 2



Q5: Have you had any of the following outcomes as a result of this use?

Answered: 142 Skipped: 6

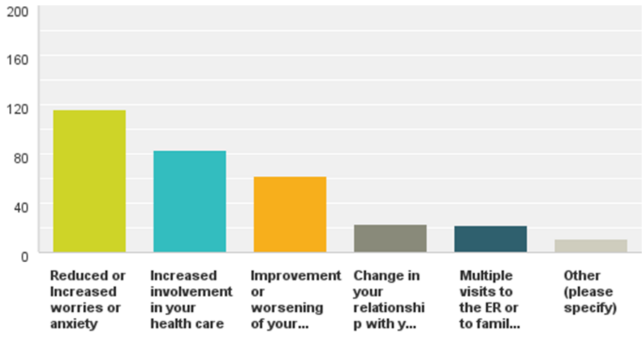
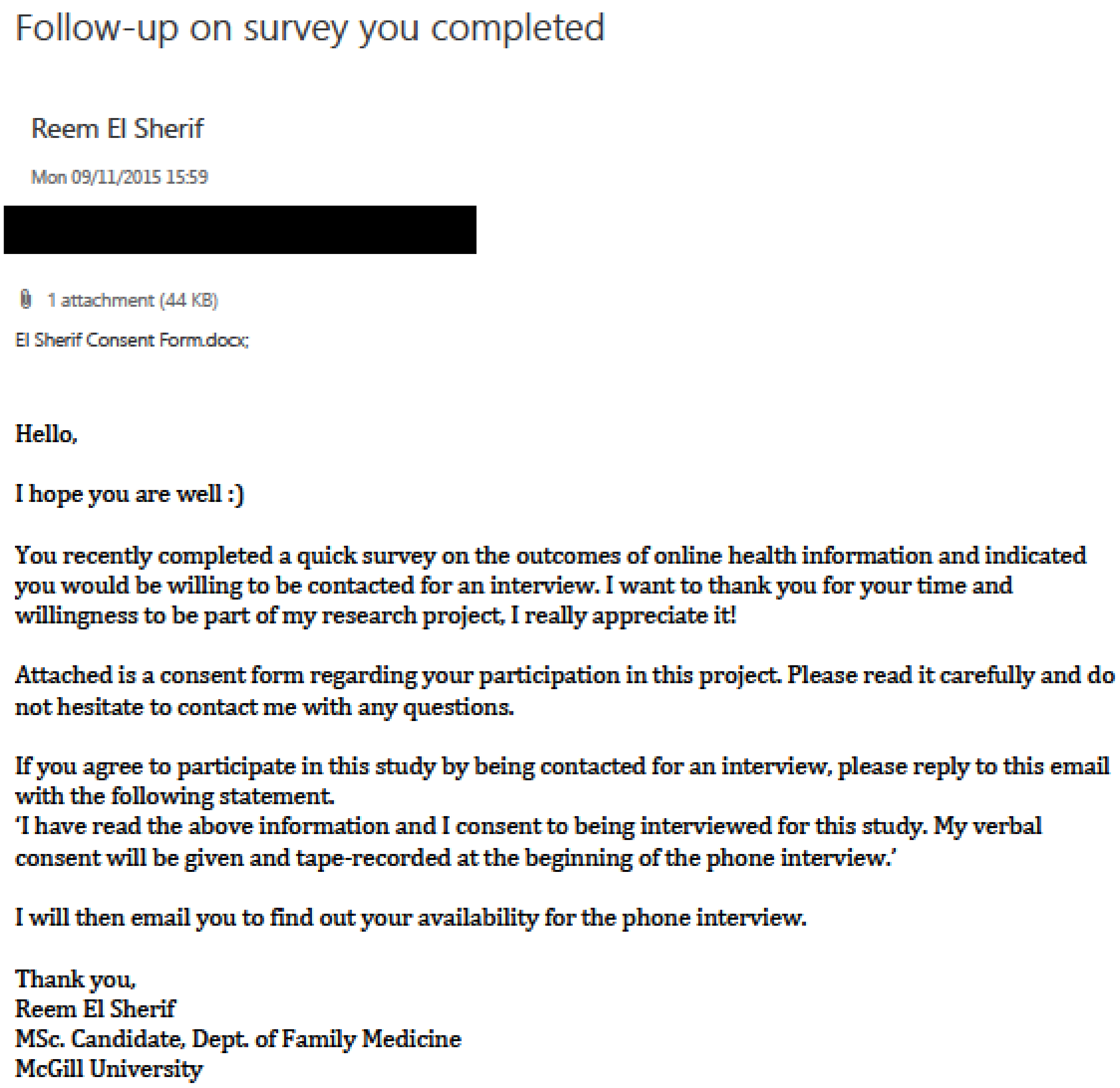


Figure 6 Email sent to consumers



Follow-up on survey you completed

Reem El Sherif

Mon 09/11/2015 15:59

[redacted]

1 attachment (44 KB)

El Sherif Consent Form.docx;

Hello,

I hope you are well :)

You recently completed a quick survey on the outcomes of online health information and indicated you would be willing to be contacted for an interview. I want to thank you for your time and willingness to be part of my research project, I really appreciate it!

Attached is a consent form regarding your participation in this project. Please read it carefully and do not hesitate to contact me with any questions.

If you agree to participate in this study by being contacted for an interview, please reply to this email with the following statement.
'I have read the above information and I consent to being interviewed for this study. My verbal consent will be given and tape-recorded at the beginning of the phone interview.'

I will then email you to find out your availability for the phone interview.

Thank you,
Reem El Sherif
MSc. Candidate, Dept. of Family Medicine
McGill University

Figure 7 Email sent to practitioners (English)

McGill | Faculty of **Medicine** Department of Family Medicine | Faculté de **médecine** Département de médecine familiale

5858 Côte-des-neiges, 3rd Floor, Suite 300
McGill University, Montréal (Québec), H3S 1Z1
Tel: (514) 399 9109 ; Fax: (514) 398 4202
www.med.mcgill.ca/familymed

Montreal, January 30, 2016

Dear (.....)

The present letter is to invite you to participate in an innovative graduate student's research project (a 30-60 minute interview at the time and location of your convenience).

Reem El Sherif is a great Master's student in the Department of Family Medicine under my supervision. Her MSc thesis project is entitled *'Pitfalls of the use of online consumer health information: What are they and how might they be prevented?'* See enclosed consent. For the first stage of her project, she conducted an amazing systematic literature review, and interviewed 20 consumers of online health information, which allowed her to identify the negative outcomes of using online consumer health information.

For the next stage, she will discuss these results with health care practitioners and health librarians who have had experience with patients/consumers using online health information to explore if and how such negative outcomes might be prevented. To this end, I invite you to participate in her project and provide your valuable insight on this topic. If you agree to participate, Reem will contact you to schedule the interview at the time and location of your convenience.

Hoping you will consider positively this invitation,

Sincerely yours,

Pierre Pluye MD, PhD

Full Professor, FRQS Senior Research Scholar
Director, Methodological Developments, Quebec SPOR-SUPPORT Unit
Department of Family Medicine, McGill University

Professeur titulaire, Chercheur boursier senior FRQS
Directeur, Développements Méthodologiques, Unité Soutien SRAP-Québec
Département de médecine de famille, Université McGill

5858 Côte-des-neiges, Suite 300
Montréal, QC, Canada, H3S 1Z1
Phone/tel: 514-398-8483
Email: pierre.pluye@mcgill.ca

Figure 8 Email sent to practitioners (French)

McGill | Faculty of Medicine / Faculté de médecine
Department of Family Medicine / Département de médecine familiale
www.med.mcgill.ca/familymed

Montréal, le 20 janvier 2016

Cher/Chère …

La présente lettre est pour vous inviter à participer à un projet de recherche innovateur sur l'utilisation d'information en ligne. Votre participation consistera en une entrevue d'une durée de 30 à 60 minutes à un lieu à votre convenance.

Ce projet est mené par une étudiante à la maîtrise au Département de médecine familiale à l'Université McGill sous ma supervision, Reem El Sherif. Son projet de thèse de maîtrise est intitulé «Les pièges de l'utilisation d'information de santé en ligne : quels sont-ils et comment pourraient-ils être évités?» (voir formulaire de consentement ci-joint). Pour la première étape de son projet, elle a effectué une revue systématique de la littérature et a interviewé 20 consommateurs d'information de santé en ligne, ce qui lui a permis d'identifier des effets néfastes de l'utilisation d'information de santé en ligne.

Pour la deuxième étape, elle prévoit recruter des professionnels de la santé et des bibliothécaires de la santé qui ont une expérience avec des patients/consommateurs d'information de santé en ligne pour explorer comment ces résultats néfastes pourraient être évités. À cette fin, je vous invite très fortement à participer à son projet et partager votre précieuse expérience sur ce sujet. Si vous acceptez de participer, Reem communiquera avec vous pour planifier une entrevue à la date, l'heure et le lieu de votre convenance.

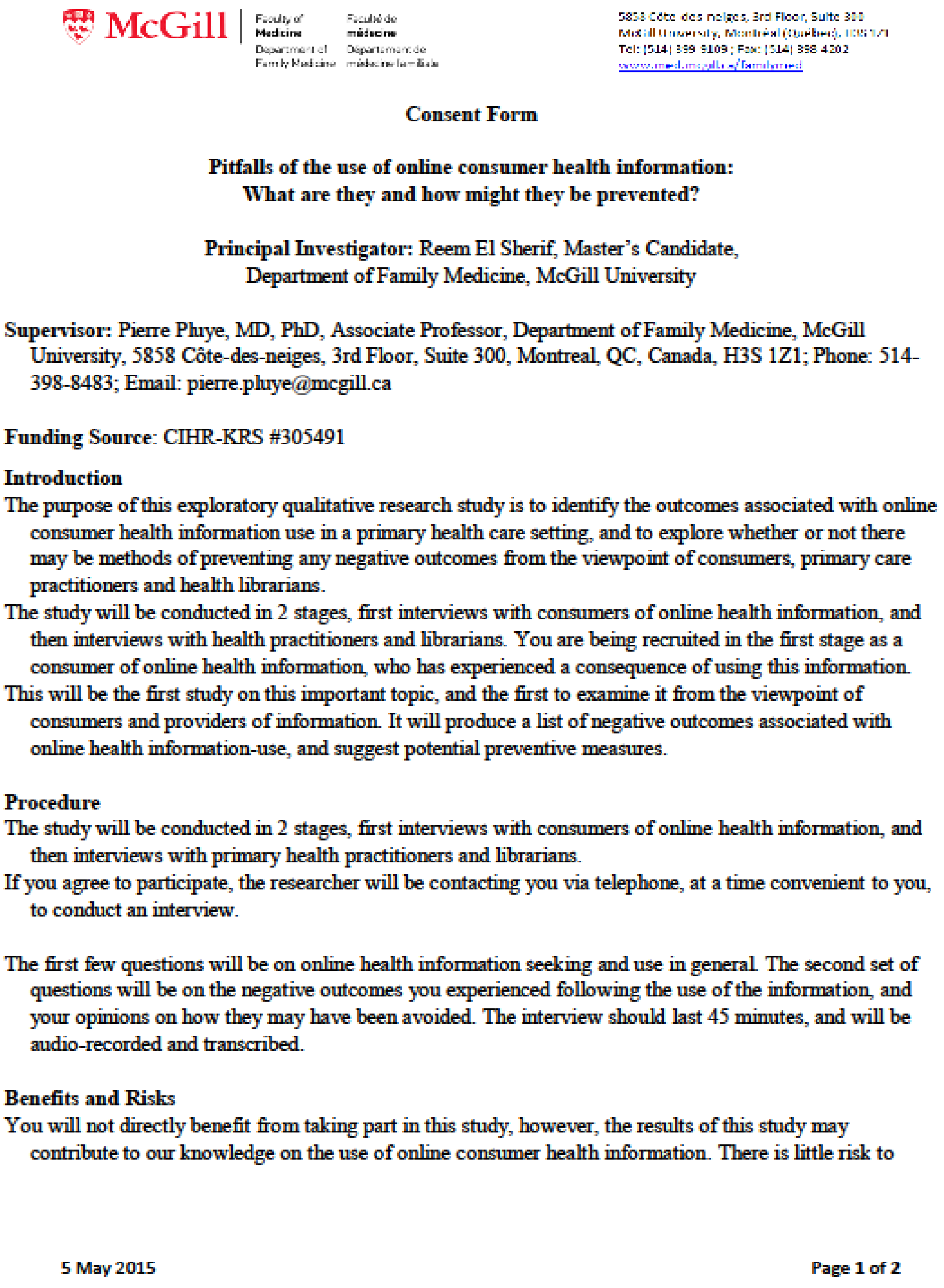
En espérant une réponse favorable de votre part, veuillez recevoir mes cordiales salutations.

Pierre Pluye MD, PhD

Professeur titulaire, Chercheur boursier senior FRQS
Directeur, Développements Méthodologiques, Unité Soutien SRAP-Québec
Département de médecine de famille, Université McGill
Tél: 514-398-8483
Email: pierre.pluye@mcgill.ca

Appendix III. Consent Forms

Figure 9 Consent Form for Consumers



McGill | Faculty of Medicine Department of Family Medicine | Faculté de médecine Département de médecine familiale

5858 Côte-des-neiges, 3rd Floor, Suite 300
McGill University, Montréal (Québec), H3S1Z1
Tel: (514) 399 9109 ; Fax: (514) 398 4202
www.med.mcgill.ca/familymed

Consent Form

Pitfalls of the use of online consumer health information:
What are they and how might they be prevented?

Principal Investigator: Reem El Sherif, Master's Candidate,
Department of Family Medicine, McGill University

Supervisor: Pierre Pluye, MD, PhD, Associate Professor, Department of Family Medicine, McGill University, 5858 Côte-des-neiges, 3rd Floor, Suite 300, Montreal, QC, Canada, H3S 1Z1; Phone: 514-398-8483; Email: pierre.pluye@mcgill.ca

Funding Source: CIHR-KRS #305491

Introduction

The purpose of this exploratory qualitative research study is to identify the outcomes associated with online consumer health information use in a primary health care setting, and to explore whether or not there may be methods of preventing any negative outcomes from the viewpoint of consumers, primary care practitioners and health librarians.

The study will be conducted in 2 stages, first interviews with consumers of online health information, and then interviews with health practitioners and librarians. You are being recruited in the first stage as a consumer of online health information, who has experienced a consequence of using this information.

This will be the first study on this important topic, and the first to examine it from the viewpoint of consumers and providers of information. It will produce a list of negative outcomes associated with online health information-use, and suggest potential preventive measures.

Procedure

The study will be conducted in 2 stages, first interviews with consumers of online health information, and then interviews with primary health practitioners and librarians.

If you agree to participate, the researcher will be contacting you via telephone, at a time convenient to you, to conduct an interview.

The first few questions will be on online health information seeking and use in general. The second set of questions will be on the negative outcomes you experienced following the use of the information, and your opinions on how they may have been avoided. The interview should last 45 minutes, and will be audio-recorded and transcribed.

Benefits and Risks

You will not directly benefit from taking part in this study, however, the results of this study may contribute to our knowledge on the use of online consumer health information. There is little risk to

5 May 2015 **Page 1 of 2**

participating in this study; participant may recall a negative experience that may upset them. The researcher will replace your name with a pseudonym, and transform any information that may identify you. The interview will be recorded to help the researcher to clarify her notes as needed.

Voluntary participation

It is entirely your choice whether you participate in this study or not. You may refuse to participate or you may decide to withdraw from this study at any time. If you withdraw consent, any data collected up until the point of your withdrawal will be kept by the researcher with your permission.

Compensation

As a token of appreciation for your time, a $20 e-gift card to a Canadian retailer of your choice (e.g., Chapters) will be emailed to you after the interview.

Confidentiality

The information will remain confidential; No identifying information will be published in scientific articles or disclosed during presentations. The researcher will replace names with a pseudonym, and transform any information that may identify interviewees. so that, apart from the researcher, no one can identify you. All data study will be stored on the researcher's password protected external hard drive. Only the researcher and her supervisor will have access to this data. Any paper copies will be destroyed after analysis of the results. Members of the McGill Institutional Review Board, or persons designated by the McGill Institutional Review Board, may access the study data to assess the ethical conduct of this study. Data will be retained on an external hard drive for 7 years after publication as per University policy.

Contact

For any further questions about the study, please contact Reem El Sherif (reem.elsherif@mail.mcgill.ca) or Dr. Pierre Pluye (pierre.pluye@mcgill.ca).

For any questions about the rights of research participants, please contact the McGill Institutional Review Board: Ms. Ilde Lepore (ilde.lepore@mcgill.ca)

Conclusion

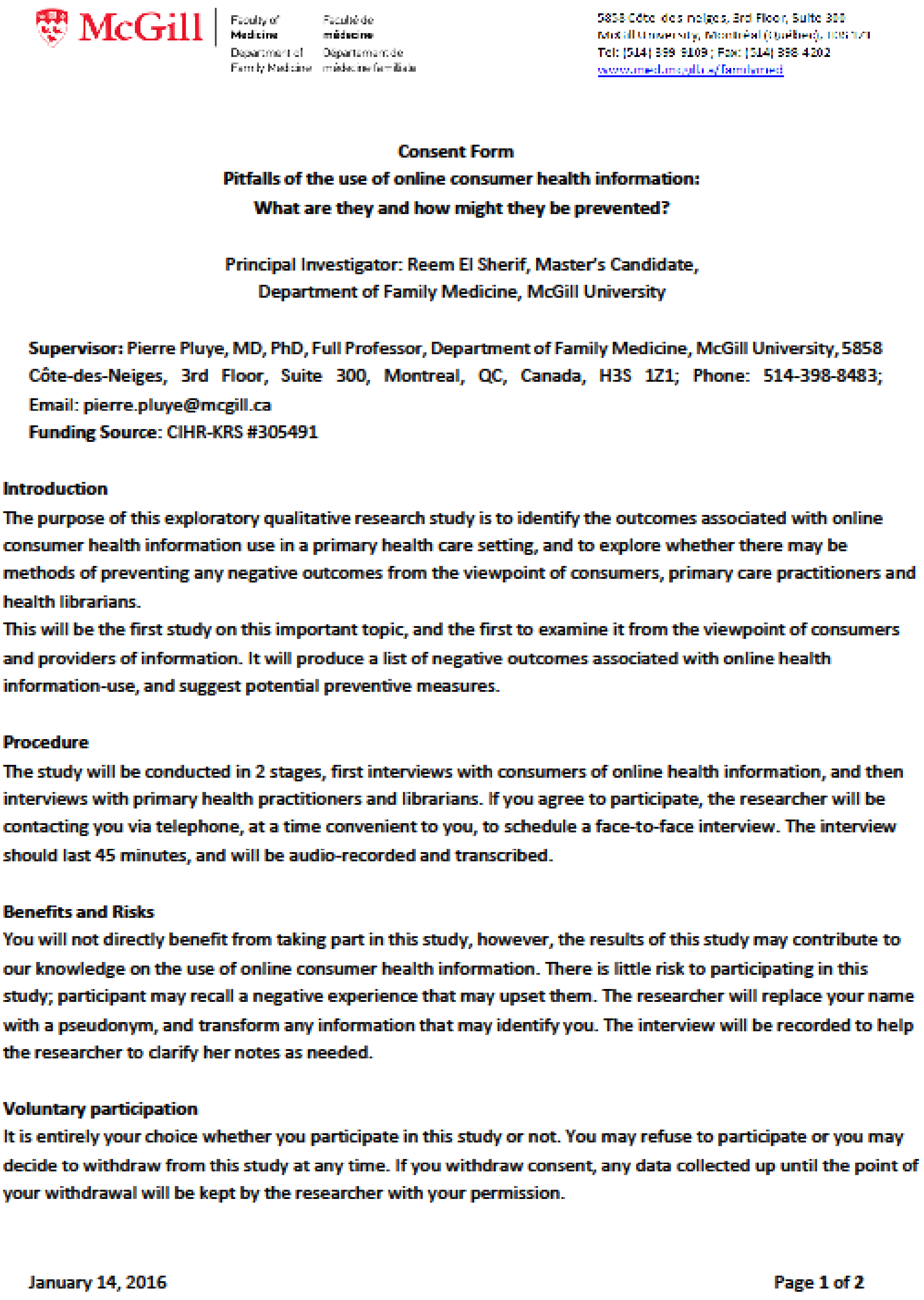
If you agree to participate in this study by being contacted for an interview, please reply to this email with the following statement.

'I have read the above information and I consent to being interviewed for this study. My verbal consent will be given and tape-recorded at the beginning of the phone interview.'

I will then email you to find out your availability for the phone interview.

A discussion on consent will take place at the beginning of the phone interview, and your verbal consent will be audio-recorded.

Figure 10 Consent Form for Practitioners



McGill
Faculty of Medicine
Department of Family Medicine
Faculté de médecine
Département de médecine familiale

5858 Côte-des-neiges, 3rd Floor, Suite 300
McGill University, Montréal (Québec), H3S 1Z1
Tel: (514) 399 9109 ; Fax: (514) 398 4202
www.med.mcgill.ca/familymed

Consent Form

Pitfalls of the use of online consumer health information: What are they and how might they be prevented?

Principal Investigator: Reem El Sherif, Master's Candidate,
Department of Family Medicine, McGill University

Supervisor: Pierre Pluye, MD, PhD, Full Professor, Department of Family Medicine, McGill University, 5858 Côte-des-Neiges, 3rd Floor, Suite 300, Montreal, QC, Canada, H3S 1Z1; Phone: 514-398-8483; Email: pierre.pluye@mcgill.ca
Funding Source: CIHR-KRS #305491

Introduction

The purpose of this exploratory qualitative research study is to identify the outcomes associated with online consumer health information use in a primary health care setting, and to explore whether there may be methods of preventing any negative outcomes from the viewpoint of consumers, primary care practitioners and health librarians.

This will be the first study on this important topic, and the first to examine it from the viewpoint of consumers and providers of information. It will produce a list of negative outcomes associated with online health information-use, and suggest potential preventive measures.

Procedure

The study will be conducted in 2 stages, first interviews with consumers of online health information, and then interviews with primary health practitioners and librarians. If you agree to participate, the researcher will be contacting you via telephone, at a time convenient to you, to schedule a face-to-face interview. The interview should last 45 minutes, and will be audio-recorded and transcribed.

Benefits and Risks

You will not directly benefit from taking part in this study, however, the results of this study may contribute to our knowledge on the use of online consumer health information. There is little risk to participating in this study; participant may recall a negative experience that may upset them. The researcher will replace your name with a pseudonym, and transform any information that may identify you. The interview will be recorded to help the researcher to clarify her notes as needed.

Voluntary participation

It is entirely your choice whether you participate in this study or not. You may refuse to participate or you may decide to withdraw from this study at any time. If you withdraw consent, any data collected up until the point of your withdrawal will be kept by the researcher with your permission.

Compensation

As a token of appreciation for your time, a $20 e-gift card to a Canadian retailer of your choice (e.g., Chapters) will be emailed to you after the interview.

Confidentiality

The information will remain confidential; no identifying information will be published in scientific articles or disclosed during presentations. The researcher will replace names with a pseudonym, and transform any information that may identify interviewees so that, apart from the researcher, no one can identify you. All data study will be stored on the researcher's password protected external hard drive. Only the researcher and her supervisor will have access to this data. Any paper copies will be destroyed after analysis of the results. Members of the McGill Institutional Review Board, or persons designated by the McGill Institutional Review Board, may access the study data to assess the ethical conduct of this study. Data will be retained on an external hard drive for 7 years after publication as per University policy.

Contact

For any further questions about the study, please contact Reem El Sherif (reem.elsherif@mail.mcgill.ca) or Dr. Pierre Pluye (pierre.pluye@mcgill.ca). For any questions about the rights of research participants, please contact the McGill Institutional Review Board: Ms. Ilde Lepore (ilde.lepore@mcgill.ca)

Conclusion

If you agree to participate in this study by being contacted for an interview, please reply to this email. Reem El Sherif will then contact you to find out your availability for interview. A discussion on consent will take place at the beginning of the interview.

Signature

The study has been explained to me and my questions have been answered to my satisfaction. A copy of this form will be provided to me for my records. After reviewing the above information, I agree to participate in this study.

Signature of the participant: ______________________________________

Please print your name: ____

Date: _________________________

Signature of the principal investigator: ______________________________

Appendix IV. Interview Guides

Interview with consumers in Stage 1

Introduction

Thank you for agreeing to being contacted for this interview. You may recall, you recently answered a few questions on the use of online health information on an online survey. You had stated that you had experienced a negative outcome of some sort after using online health information, and that experience will be the subject of this interview.

I am a Master’s student in the department of Family Medicine at McGill University, and the topic of my thesis project is the negative outcomes associated with the use of online consumer health information, and how they may be prevented.

I want to state that this interview is completely confidential, and that I will be recording it to transcribe later, but all personal details will be omitted in the analysis

Before we start, do you have any questions?

Screening Question

Are you currently on any medication or being treated for any long-term disease?

Questions on information-use

1) When do you seek health information online?
2) Could you elaborate on the circumstances that lead you to look for health information online?
3) How did you look for the information?
4) (Prompt: Could you describe the process?)
5) Did you find information you were looking for?
6) If not, why do you think you did not?
7) If you did find the information, did you understand it/did it make sense to you?
8) If not, why not?
9) How did you use the information?

Questions on negative outcomes

10) After using the information, what outcomes did you experience? (What happened next?)
11) Would you describe any of these outcomes as negative?
12) In what way?
13) May you describe what happened?
14) How do you think these negative outcomes could have been avoided?

15) Are there any other details you would like to add/mention?

Thank you very much for your time.

Interview with health practitioners and librarians in Stage 2

Introduction

Thank you for agreeing to being contacted for this interview. You had stated that you had experience with consumers/patients who had experienced a negative outcome of some sort after using online health information, and that experience will be the subject of this interview.

I am a Master's student in the department of Family Medicine at McGill University, and the topic of my thesis project is the negative outcomes associated with the use of online consumer health information, and how they may be prevented.

I want to state that this interview is completely annonymous, and that I will be recording it to transcribe later, but all personal details will be omitted in the analysis.

Before we start, do you have any questions?

At an earlier stage in the project I had interviewed consumers who had experienced negative outcomes, and developed 2-3 vignettes from their stories. Could you please read these vignettes before we proceed?

Questions on consumer information-use and negative outcomes

1) What do you think of these stories?
2) Do you believe these are common outcomes of information use?
3) Have you had experience with these negative outcomes?
4) Could you elaborate on your experience with consumers who have used online health information?
5) Could you describe the negative outcomes associated with this use?
6) What factors do you believe contributed to the development of these negative outcomes?
7) How do you think these negative outcomes could have been avoided?
8) What factors do you believe led to these negative outcomes?
9) *If the vignette involves a practitioner/librarian* What would you have done differently?
10) *Only with physicians* How do you view patients who seek online health information?

11) Are there any other details you would like to add/mention?

Thank you very much for your time.

Appendix V. Thematic Analysis Codebook

Stage 1

Codes derived from analysis of interviews	Themes and subthemes
1. Context for looking for OCHI	Theme 1. Motivation for searching for health information online
	Subtheme 1.1 Searching for information for themselves
	Subtheme 1.2 Hypochondria
	Subtheme 1.3 Searching for information for someone else
2. Seeking behaviour and types of OCHI	Theme.2 Strategies for searching for information online
2.1 Relevance of the information	Subtheme 2.1 Using a search engine (Google)
	Subtheme 2.2 Using a renowned medical website
	Subtheme 2.3 Using websites or forums with patient experiences
	Subtheme 2.4 Strategies for evaluating OCHI websites
2.2 Understanding the information	Theme 3. Making sense of the information
	Subtheme 3.1 Understanding the information found
	Subtheme 3.2 Gaining general knowledge without answering a specific question
	Subtheme 3.3 Not finding the answer to a specific health question
	Subtheme 3.4 How health literacy influences understanding
3. Use of OCHI	Theme 4. Decision-making after finding relevant OCHI
3.1 To decide on consulting a physician	Subtheme 4.1. Deciding whether or not to book a medical appointment
	Subtheme 4.2 Postponing a medical appointment due to limited access
3.2 To make a healthcare decision	Subtheme 4.3 Making a health care decision
	Subtheme 4.4 Stopping a medication
3.3 To prepare for a physician encounter	Subtheme 4.5 Discussion in a physician encounter
	Subtheme 4.6 To confirm a physician’s diagnosis
4. Positive Outcomes	Theme 5. Positive outcomes of using OCHI from a consumer perspective
	Subtheme 5.1 Requesting a test to aid diagnosis
	Subtheme 5.2 Feeling reassured about a physician-recommended management plan
	Subtheme 5.3 Being better prepared for a clinical appointment
5. Negative outcome	Theme 6. Negative outcomes of OCHI from consumer perspective
5.1 Increased anxiety	Subtheme 6.1 Increased worrying
5.2 Negative health consequence	
5.3 Patient-physician relationship	
5.4 Tension with family members	Subtheme 6.2. Tension with family members
5.5 .Healthcare system over-use	Subtheme 6.3. Postponing seeking medical help for a health problem
5.6 Ignoring a serious symptom	
6. Ways of preventing negative outcomes	Theme 7. Strategies for preventing negative outcomes of OCHI from a consumer perspective
6.1 Manage consumer expectations on OCHI	Subtheme 7.1 Be aware of limitations of OCHI
6.2 Be careful what you follow	Subtheme 7.2 Reliable and relevant sources of OCHI
6.3 Change in the OCHI	
6.4 Have physician provide search parameters for reliable information	Subtheme 7.4 Follow physician provided OCHI or search parameters
6.5 Discuss with physician or social network	Subtheme 7.3 Discuss OCHI with physician, telehealth or members of social network
6.6 Nurse hotline	
7. General ideas or opinions	

Stage 2

Codes derived from analysis of interviews	Themes and subthemes
1. Types of OCHI	Theme 1. Types of OCHI
	Subtheme 1.1 General health information
	Subtheme 1.2 Forums and patient-sourced information
1.1 Alternative and complimentary OCHI	Subtheme 1.3 Alternative medicine information
1.2 Anti-vaccination	Subtheme 1.4 Anti-vaccination information
2. Positives of OCHI	Theme 2. Advantages of OCHI
2.1 Discussion of OCHI during a clinical encounter	Subtheme 2.1 Informed and involved patients
	Subtheme 2.2 More productive clinical encounters
	Subtheme 2.3 Introduce a new or alternative management option
3. Negative outcomes from practitioner perspective	Theme 3. Negative outcomes of OCHI
3.1 Increased anxiety	Subtheme 3.1 Increased worrying
3.2 Spending money on useless products	Subtheme 3.2 Spending money on non-beneficial products
3.3 Pt-physician relationship affected	Subtheme 3.3 Tension in the provider-patient relationship
3.4 Non-adherence to management plan	Subtheme 3.4 Non-adherence to management plan
3.5 Postponing seeing a specialist	Subtheme 3.5 Postponing seeking medical help
4. Factors influencing outcomes	Theme 4. Factors influencing outcomes
	Subtheme 4.1 Individual characteristics
	Subtheme 4.2 Information avoidant personalities
	Subtheme 4.3 Access to health care services
5. Strategies for preventing pitfalls	Theme 5. Strategies for preventing negative outcomes
5.1 Provide reliable resources	Subtheme 5.1 Provide reliable sources of OCHI
5.2 Teach consumers how to evaluate OCHI	Subtheme 5.2 Teach people how to evaluate OCHI
5.3 Discuss the info with patient	Subtheme 5.3 Discuss OCHI during a clinical encounter
5.7 Strategies to facilitate discussion with health care provider	
5.5 Alternative, natural, complimentary treatments	Subtheme 5.4 Handling OCHI on alternative treatments/non-conventional therapies
5.6 Librarians role	Subtheme 5.5 Health librarians' role
5.4 Changing health provider attitudes	Subtheme 5.6 Change health care provider attitudes
6. Opinions on OCHI	Theme 6. General opinion of participants on OCHI
Reliable sources of OCHI from practitioner perspective	
Patient anecdotes	