



TECHNICAL REPORT

A literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective

Insights into health communication

ECDC TECHNICAL REPORT

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**Clínica
Universidad
de Navarra**



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Contents

Executive summary	1
Introduction	2
Rationale for the review	2
Objectives of the review	2
Structure of the review	2
Methodology	3
Search strategy	3
Search terms	3
Exclusion/inclusion criteria	3
Results	4
Internet accessibility and usage patterns	4
Online health information consumer profile	5
Online sources of information	5
Internet use by health professionals	6
Challenges for health professionals	8
Summary of findings	9
Implications for health communication research in Europe	9
Insights for health communication policy and practice	9
Identification of gaps and focus for further research	9
References	11

Executive summary

The purpose of this literature review is to provide an overview of research studies published from 2006 to 2010 in the English language on online health information-seeking behaviour by adults from the perspective of both the health consumer and the health professional.

Interest in the internet as a communication tool for health-related information is growing rapidly [1]. The profile of online health consumers can be broadly defined as patients, patients' friends/relatives, and citizens in general [2]. Health information-seeking behaviour varies depending on type of information sought, reasons for, and experience of, searching [3]. Research shows that women are more likely than men to search for health information [4,5] and online health consumers tend to be more educated, earn more, and have high-speed internet access at home and at work [6,7]. Internet-based health information is accessed from a variety of sources, including websites run by organisations, homepages run by individuals, and online support groups where people actively exchange health information and blogs. As more people use the internet as a source of health information the issue of source credibility and trust in websites becomes important [8].

Research shows that health professionals' use of the internet to obtain health and medical information has increased [9–11]. Furthermore, in a cross-sectional survey, 80% of physicians reported experience of patients presenting printed internet-sourced health information at visits [12]. Thus, the traditional doctor–patient relationship is being challenged.

The internet is a resource available to an increasing number of European citizens but, as with other information sources, differential access and use is apparent both within countries and between countries in the European Union. A lack of research in the European context means that the potential of the internet as a source of health information may not be fully understood. Nevertheless, the internet would appear to provide the ideal medium for the provision of information targeted at the prevention and control of communicable disease for both health consumers and health professionals in Europe.

Introduction

Rationale for the review

Public health communication initiatives must use the most effective strategies for the promotion, protection and maintenance of health. This can be achieved through using the best available evidence to guide and inform practice and policy. Practitioners, programme managers and policymakers need to be aware of what is known about the benefits, risks and costs of communication interventions aimed at the prevention and control of communicable disease. Summaries of existing knowledge compiled in a series of reviews of what is currently known can provide a powerful resource for practitioners and policymakers. Such reviews also enable researchers to focus their attention on identified gaps in knowledge. This review is one in a series of 'Insights into health communication' on the prevention and control of communicable disease in the European context. Due to the diversity of issues relating to the research on health information-seeking behaviour on the web from both health consumers' and health professionals' perspectives this literature review should be seen as providing an overview of the topics and an introduction to the related issues.

Objectives of the review

The purpose of this literature review is to provide an overview of online health information-seeking behaviour by adults from the perspective of both the health consumer and the health professional. The review crosses a number of disciplines including communication science, medicine, health promotion, social marketing, psychology and information technology.

Specific objectives include:

- documenting internet accessibility and usage patterns;
- outlining online health information consumer profiles;
- identifying online sources of health information;
- outlining health professionals' internet use; and
- ascertaining challenges for health professionals posed by internet use.

Structure of the review

First the methodology used to undertake this review is described with reference to inclusion and exclusion criteria, keywords used and databases searched. The review itself is divided into three main sections:

- the internet and health information, including internet usage and penetration across Europe;
- health consumers on the web; and
- health professionals on the web including the challenges faced.

Finally, consideration is given to the issues raised by the review and the implications for public health practice and further research.

Methodology

Search strategy

A number of databases were used in the search for relevant academic published articles including Scopus, PubMed, Web of Knowledge and Business Source Premier. Searches for grey literature on the topic area were conducted using Google. Articles for the review were drawn from peer-reviewed journals, conference papers, consumer studies, health professional studies, research by recognised independent institutions as well as systematic and narrative reviews of the various topics.

Search terms

The terms used for search purposes included, but were not restricted to: 'internet/web/online health seeking behaviour', 'online health information', 'e-health' and 'communicable disease'.

Exclusion/inclusion criteria

Due to the breadth of subjects covered, the literature review concentrates on research published from 2006 to 2010. The study excluded research published before 2006 and also excluded non-English language publications.

Results

A general breakdown of the papers referenced by research location is as follows: International (reviews) – 3; US – 22; Europe – 14; Canada – 2; US/Canada – 1; Australia – 1.

Internet accessibility and usage patterns

New digital technologies have become an increasingly important part of the daily lives of many people around the world. While statistics can vary due to differences in research methodologies, as of the end of December 2009 there were an estimated 1.8 billion internet users worldwide [13]¹. The majority of these are located in Asia (42.4%) followed by Europe (23.6%) and North America (14.4%). However, North America has the greatest internet penetration rate (percentage of the population who use the internet) at 76.2% with Oceania/Australia at 60.8% and Europe at 53% second and third on the list, respectively. The world average internet penetration rate is 26.6%. These figures represent a worldwide growth in internet use of almost 400% from 2000 to 2009 and indicate that the internet is becoming an established medium for the dissemination of targeted messages to specific audiences [14]. Table 1 illustrates internet access by country across the EU.

Table 1. Internet access and broadband connection by households in the European Union, 2009

European Union	Internet access	Broadband connection
Austria	70%	58%
Belgium	67%	63%
Bulgaria	30%	26%
Cyprus	53%	47%
Czech Republic	54%	49%
Denmark	83%	76%
Estonia	63%	62%
Finland	78%	74%
France	63%	57%
Germany	79%	65%
Greece	38%	33%
Hungary	55%	51%
Ireland	67%	54%
Italy	53%	39%
Latvia	58%	50%
Lithuania	60%	50%
Luxembourg	87%	71%
Malta	64%	63%
Netherlands	90%	77%
Poland	59%	51%
Portugal	48%	46%
Romania	38%	24%
Slovakia	62%	42%
Slovenia	64%	56%
Spain	54%	51%
Sweden	86%	80%
United Kingdom	77%	69%

Source: Eurostat [15].

Technology is proving to be a means by which 'an increasing number of ordinary people, professionals and organisations are relying on the internet for information and other purposes' [14]. Interest in the internet as a communication tool for health-related information is also growing rapidly [1,12,16-23] and the proliferation of the medium has, it can be argued, changed the way people use information to protect their health [24].

¹ These numbers continue to increase, as shown by more recent data from Internet World Stats (<http://www.internetworldstats.com/stats.htm>) available after this literature review was done: 2.09 billion internet users worldwide as of 31 March 2011.

- A 2009 survey by the Pew Internet & American Life Project (which conducted telephone interviews with a national sample of 2 253 US adults) found that '8 in 10 internet users or 61% of U.S. adults have looked online for health information' [5].
- This is also in line with the findings from a 2008 Harris Poll, which conducted a telephone survey of a national sample of 1 010 US adults, and found that 81% of those online have used the internet to obtain health information [25].
- In Europe, a WHO eHealth cross-country survey of seven countries² shows '71% of internet users had used the internet for health purposes' [16].

Online health information consumer profile

In the context of studies on health information seeking online, 'health consumers' can be broadly defined as patients, patients' friends/relatives, and citizens in general [2], and 'health seekers' have been defined as 'internet users who search online for information on health topics, whether they are acting as consumers, caregivers or e-patients' [26]. While the literature shows little uniformity in the methods used to research health consumers' information-seeking behaviour on the internet, a number of generalisations can be drawn from the findings. Another characteristic of this body of literature is a relative lack of reference to health consumer information-seeking behaviour in relation to communicable disease specifically. The main areas covered by the literature include internet health consumer characteristics, search behaviour, search motivations and utilisation of information.

Health information seeking is associated with a wide variety of factors and 'search behaviour varies depending on type of information sought, reasons for searching and experience levels' [3]. Current research shows that females are more likely than males to search for health information [4,5,16,18] and online health consumers tend to be more educated, earn more and have high-speed internet access at home and at work [6,7]. Health consumers use the information they source online in different ways.

- The WHO eHealth survey indicates that 29% had used information from the internet to decide whether they needed to see a doctor, and of those that did attend, one in four used the internet in conjunction with the doctor's appointment [23].
- In the latest Pew Internet Project survey, 59% of newly diagnosed patients stated that the information they had accessed prompted them to ask questions of the doctor or seek a second opinion [27].

Health status also has implications for the use of online sources. Andreassen et al. state that 'medical indicators of health, such as current diagnosis of long-term illness or disability, and a high number of visits to the general practitioner, indicate a higher level of health-related use of the internet' [16]. This is supported by Ybarra & Suman [28] using data from *Surveying the Digital Future Year 4*, a nationally representative US telephone survey of 2 010 respondents.

- This study highlighted the fact that the internet health information-seeking experience is probably influenced by age-specific lifestyle trends and typical health status as well as disease risk changes as a result of ageing [28].
- 2007 figures from Pew support these findings and its survey shows that 'people who feel they have a lot at stake are more likely to engage intensely with online resources' [27].
- A 2006 study of 347 men and 72 women in the US living with HIV/AIDS, for example, found that two thirds of the participants searched for health information at least half the time they were online [29].

Ybarra & Suman also indicate that the 'most common reason adolescents used the internet [as a health resource] was to search for information about a personal problem whereas young adults and middle-aged adults were most likely to use the internet to search for information about a condition of a loved one'. These findings are supported by Andreassen et al. who also state that in Europe the most active health users are the 30-to-44 age group [16]. According to a Pew survey, half of all online health enquiries in the US are on behalf of someone other than the person conducting the search. The literature also indicates that online health information seekers generally feel more reassured having consulted health information sites [16,23,26,28].

Online sources of information

Internet-based health information is accessed from a variety of sources, including,

- websites run by organisations;
- homepages owned by individual doctors;

² As part of the WHO/European survey on e-health consumer trends, representative samples were obtained from the general populations of Norway, Denmark, Germany, Greece, Poland, Portugal and Latvia. Interviews were conducted by telephone and there were 7 934 respondents in total.

- online support groups where people actively exchange health information; and
- blogs authored by health advocates, caregivers or those pursuing self-help [30].

A US Pew survey indicates that the majority of health information seekers there (66%) begin their search process at search engines such as Google or Yahoo, with 27% using a specific health-related website to start the search [26].

- Almost 80% go on to search multiple sites [26]. According to McMullan and Gallagher et al., the majority of health-related internet searches by patients are for specific medical conditions [18,31].
- This is backed up by findings from the Pew survey where 49% of health information seekers searched for 'a specific disease or medical problem' [5].
- Other topics searched include looking for information on a medical treatment or procedure (41%), prescription or over-the-counter drugs (33%), alternative treatments or medicines (26%) and depression, anxiety, stress or mental health issues (21%) [5].

'Technology is not an end, but a means to accelerate the pace for discovery, widen social networks, and sharpen the questions someone might ask when they do get to talk to a health professional' [5]. In addition to using the internet to browse for information, there are other health-related activities identified by the literature. In Andreassen et al.'s cross-country European study, the authors found that 27% had participated in online forums or self-help groups and 30% had interacted with health professionals [16]. A Pew research study in the US found that 'a majority of e-patients access user-generated health information' with 41% having read a commentary/blog/newsgroup about a particular health or medical issue [5]. According to Lustria, interactivity can significantly increase comprehension of online content but the author also cautions that 'the challenge is how to strike a balance between providing an engaging and visually appealing website, and providing a site that the least competent information seeker could easily navigate without too much guesswork' [22].

As more people use the internet as a source of health information, the issue of source credibility and trust in websites becomes important. According to a survey conducted by Sillence et al. [8], the top five most important trust markers for health websites in 2005 in order of importance were:

- the site was easy to use;
- the advice came from a knowledgeable source;
- the advice appeared to be prepared by an expert;
- the advice appeared to be impartial and independent; and
- the reasoning behind the advice was explained to me.

However, earlier findings in the US indicate that there are about 85 million Americans gathering health advice online without consistently examining the quality indicators of the information they find [26].

Despite the proliferation of information available, any electronic health tool is of little use if people do not have the skills to actively engage with it [32]. Citing a 2005 report from the US Institute of Medicine entitled *Health Literacy: A Prescription to End Confusion*, Norman & Skinner say that 'those with limited literacy skills have less knowledge of disease management and health promoting behaviours, report poorer health status and are less likely to use preventive services than those with average or above average literacy skills' [32]. Atkinson et al. identify the importance of taking account of audiences' literacy levels when developing materials [4] and, in a study of 1 000 people in Iceland and how they look for health and lifestyle information on the internet, Palsdottir states that 'those who lack experience in seeking online information and also the necessary knowledge to recognise when they need support to be able to use the internet efficiently to gather information, will be placed on the wrong side of the digital divide' [33].

Internet use by health professionals

Research shows that health professionals' use of the internet to obtain health and medical information has also increased [9–12,34,35]. In an article in a 2010 edition of the *New England Journal of Medicine* the authors go so far as to state that 'nothing has changed clinical practice more fundamentally than one recent innovation: the internet' [35]. However, the wealth of information available means that 'healthcare professionals are increasingly finding that they have more information available than they can handle with confidence in their busy time schedules' [36] and 'the hardest task now is to actually locate the information required from the flood of information received' [37]. The literature also highlights the difficulty of identifying and filtering the most useful, accurate and credible sources while searching online for health information [35–37].

As with research on health consumers, the dangers involved in drawing definitive conclusions from the literature reviewed in relation to health professionals on the web is that there is little consistency between the subject matter of the research undertaken and the methodologies and terminologies used. While there are a very limited number of comparative studies assessing health professionals' online health information-seeking behaviour, small studies within professions such as nurses and general practitioners have been undertaken [11]. There are a number of general inferences that can be highlighted particularly in relation to health professionals' motivations for using the

internet, how the search is undertaken, barriers to use, evaluation of source credibility and utilisation of information sourced.

In a systematic review of 38 studies from 1994 to 2004 as to why doctors use the internet, Masters indicated that 'consistently, doctors use the internet more than their national average and their activities focus on the use of email, retrieving information from online journals, attending courses and conferences, receiving professional updates and performing professional and administrative functions' [38]. In another review on internet-based information-seeking behaviour amongst doctors and nurses based on 23 studies between 1995 and 2009, Younger found that doctors need online information for clinical care, continuing professional development and patient information [11]. The review also outlines that doctors are more likely to 'use local reference collections (usually print) as their first port of call for information' and that 'electronic information sources were a good second choice although most were not comfortable with their searching skills' [11]. According to Davies' review, the top three categories of information requirements are 'treatment or therapy, followed by diagnosis and then, a distant third, by drug therapy/information' [37]. Quoting a 2006 study by MaxMD, Schiavo states that US physicians 'spend at least 50 minutes per night online researching disease information, drug information, and to a lesser degree, Continuing Medical Education information' [14].

- A study of public health professionals in the Massachusetts Department of Public Health found that the 'information needs of the public health workforce have become all the more urgent with the increasing frequency of emergence of new infectious diseases such as severe acute respiratory syndrome (SARS) and Asian bird flu, as well as the increasing concern about acts of bioterrorism' [39].
- Another survey by Prendiville on 156 hospital-based paediatricians in Ireland discovered that 'web-based paediatric resources are of increasing significance in the day-to-day clinical practice of evidence-based medicine, be that in performing literature searches, downloading medical images or providing information prescriptions for patients and their families' [10].
- 'Doctors need to be able to refresh their memories and update their knowledge efficiently and effectively' but these studies show that 'as with any profession, the (information) need varies amongst the population and is not homogenous' [37].

In a Missouri-based study by De Leo et al. it was found that a majority of the 381 physicians surveyed (92%) eschewed web browsing on sites such as Google in favour of targeted sites and portals such as WebMD, Pubmed and Medline [34]. Of the targeted sites used, the researchers found that physicians use 'edited/secondary data sources as their primary medical information data retrieving, about one quarter of the physicians indicated research databases which provide access to medical journal publications, a minority of physicians use sites dedicated to their specialised area and a small percentage use medical web site portals'. As cited in Prendiville, a 2007 study by Kitchin & Applegate investigated Google and found that it is increasingly being used by a younger demographic of health professional as their first port of call [10]. Prendiville's own survey of paediatricians shows that 88% considered web-based resources as essential for medical practice [10]. 57% reported using Pubmed as their main resource with a significant number using a general search engine such as Google [10].

In a study in the British Medical Journal, researchers also found that, out of 26 medical situations investigated, 'Google searches found the correct diagnoses in 15 of the cases' cautioning that 'using Google to search for a diagnosis is likely to be more effective for conditions with unique symptoms and signs that can easily be used as search terms' and 'depends on the searchers' knowledge base' [9]. A 2008 study by Andrews (cited by Prendiville) stated that the Google challenge could be summed up 'as not simply knowing where to find the information, but knowing what to do with the information once we have it' [10]. In any case 'physician preferences for online information sources may vary according to physician speciality and task specificity' [14].

While there is an increasing interest in, and use of, the internet by health professionals to obtain information, there are still a number of barriers evident.

- Barriers include technology access, the limited time available to the health professional to undertake the search, the lack of coherent available information, the diversity of sites, lack of search skills and confidence in their ability and the difficulty in evaluating site effectiveness and credibility [10,11,14,38,39].
- In Davies' review, two-thirds of the studies mentioned a lack of time and half the limited research skills of the doctors [37].
- Search skills among nurses also highlighted 'a limited range and amount of simple search terms used, low variety of websites visited and the fact that sources were only selected on the basis of convenience' [40].
- Information and website evaluation is also a key consideration and it has been identified that, in relation to medicine particularly, it is increasingly difficult to distinguish reliable and accurate up-to-date health resources for health professionals [36]. Although it must be acknowledged that there are a number of credible sites provided by recognised institutions in relation to communicable disease such as the European Centre for Disease Prevention and Control, World Health Organization and US Centers for Disease Control and Prevention, among others.

Challenges for health professionals

The advent of the internet and a better informed health consumer has had an impact on the patient–practitioner relationship [10,31,38,41,42]. Access to health information on the web is redefining the roles of physician and patient [35] with ‘the shift in the role of the patient from passive recipient to active consumer of health information’ [31].

More patients are now bringing health information that they have sourced online to the health professional with whom they are consulting. Masters observes that ‘the high percentage (89%) of doctors reporting patients’ bringing internet information to the consultation is interesting, especially compared to the much lower percentage of doctors searching for patient-specific information in the internet (44%) or referring their patients to websites (20%)’ [38]. In a cross-sectional survey by Podichetty et al. of 285 healthcare professionals in the US, more than 80% of respondents reported experience of patients presenting printed internet-sourced health information at visits [12].

However, as outlined by Hesse et al. in their analysis of trends from three HINTS surveys (2002–2008) of 6 149 respondents sponsored by the National Cancer Institute, ‘despite a decade’s worth of exposure to health information on the internet, the public’s trust in physicians as their preferred source of health information has remained high’ while ‘trust in health information from the internet or from other sources decreased during the same period’ [43]. The authors went on to say that ‘trust may actually be increasing as consumers rely on their physicians to interpret the confusing nature of online information’. This is backed up by research from the Pew survey which finds that most people with a question about their health say they consult a health professional, the second choice is to ask friends and family and the internet and books [5].

While some health professionals are ‘seriously concerned about the quality of information that consumers are finding on the internet’, a 2001 American Medical Association survey, cited by Erdem & Harrison-Walker, stated that 55% of respondents recommended credible sites to their patients [41]. In a 2009 study, 55% of paediatricians have recommended specific websites to patients or parents, with 63% providing printed information from the internet on specific issues for families [10]. According to Wald et al. ‘the use of web-derived information can yield better informed patients with a higher likelihood of adherence and improved health outcomes’ [42] and ‘the internet can improve patients’ understanding of their medical condition and their self-efficacy’ [31]. A study into chronic illness and health seeking behaviour on the internet concurs with this, stating that the use of the internet empowers patients’ in the management of their chronic conditions resulting in an increased ability to make informed decisions about their health [44].

McMullan states that the health professional can respond to this increasing use of the internet by the health consumer in three different ways:

- the health professional in question will feel ‘threatened’ by the information and will respond ‘defensively by asserting their expert opinion’;
- there is some collaboration between the patient and the health professional ‘in obtaining and analysing the internet information’; and
- ‘reliable and accurate’ websites are recommended to the patient by the health professional’ [31].

Citing Hoffman & Novak, Erdem & Harrison-Walker state that ‘relationship trust is best achieved by allowing the balance of power to shift toward a more cooperative interaction between the physician and his/her patients’ [41] and other studies dealing with the patient–practitioner relationship also outline the importance of this cooperation [31,42]. In order to develop a trusting relationship between health professionals and patients it is important that ‘health professionals acknowledge patients’ search for knowledge, that they discuss the information offered by patients and guide them to reliable and accurate health websites’ [31]. Despite the increased engagement with the internet as a source of health information, it is seen as a supplement to healthcare rather than a replacement for professional care [5,16,23].

Summary of findings

Implications for health communication research in Europe

The internet, a dynamic interactive continually evolving medium has become an established source of health information for consumers and health professionals alike. In a European context there is a dearth of research on the internet and health information-seeking behaviour from both health consumers' and health professionals' perspectives and particularly in relation to communicable diseases. This lack of research has implications for the development of health communication initiatives, which is complicated by the nature of the many countries and cultures that make up the EU and EFTA.

The level of access by European citizens and health professionals requires monitoring. The internet is a resource available to an increasing number of European citizens but, as with other information sources, differential access and use is apparent. This inequality in access is seen between countries in the European Union, with access to any form of internet connection ranging from 30% of the population in one country to 90% in another (Table 1) [15]. It is likely that this differential in access between countries is also seen by different population groups within countries but this requires further exploration. Health communication research in Europe must take this digital divide into account to facilitate equity of access to health information for all citizens as the internet as a resource for health is harnessed. The differences in language usage between the EU and EFTA countries must also be acknowledged in terms of the presentation of health information and has implications for research with both citizens and health professionals.

Insights for health communication policy and practice

- There were an estimated 1.8 billion internet users worldwide (statistic cited as of 20 March 2010); mostly located in Asia (42.4%) followed by Europe (23.6%) and North America (14.4%). The number of users in Europe is likely to increase.
- Health information seeking is associated with a wide variety of factors, and search behaviour varies depending on type of information sought, reasons for searching, and experience levels.
- People who feel they have a lot at stake are more likely to engage intensely with online resources.
- In Europe the most active users of the internet to find health information are those aged 30–44 years.
- The majority of health information seekers (66%) begin their search process at search engines such as Google or Yahoo, with 27% using a specific health-related website to start the search.
- The majority of health-related internet searches by patients are for specific clinical conditions.
- Physician preferences for online information sources may vary according to physician speciality and task specificity.
- Some evidence suggests that an increasing number of physicians recommend credible websites to their patients.
- Engagement with the internet as a source of health information is seen as a supplement to health information as opposed to being a replacement for health professionals' face-to-face guidance.

Identification of gaps and focus for further research

There is a general lack of studies focusing on health information-seeking behaviour on the internet for health professionals and citizens in the European context specifically in relation to communicable diseases. Areas for research with health professionals and citizens from different population groupings, including those hard-to-reach, include:

- access to the internet, including skills for use;
- motivations for using the internet;
- how the search is undertaken;
- barriers to use;
- evaluation of source credibility; and
- utilisation of information sourced.

Other areas include:

- issues of trust and credibility related to internet-based health-related information; and
- the specific needs of European public health organisations, which should be identified in relation to developing websites targeting both professionals and citizens (as most available research relates to healthcare).

The internet would appear to provide the ideal medium for the provision of information targeted at the prevention and control of communicable disease for both health consumers and health professionals. This potential is restricted by the relative absence of studies, particularly on the efficacy of the use of the web for public health

communication, specifically for communicable diseases. The closing of this knowledge gap has the potential to contribute to the prevention and control of communicable diseases across Europe.

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