

Consumer Informatics: Control or Making the Most of Health Internet Websites

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Summary

Objectives: To explore how the Internet is being used as a source of information, but also as a source of consumption in certain health-related fields. Determine the negative and positive impacts of this trend, depending on the topic or quality standards of websites.

Method: Synopsis of the articles selected for the IMIA Yearbook 2011.

Results: Six papers from international peer reviewed journals have been selected for the section on health information systems.

Conclusions: The articles selected discuss issues of major concern for online health information seekers, because of their positive or negative impact on health outputs.

Keywords

Consumer informatics, online health information, e-Health, quality, ethics

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Introduction

Efforts have been undertaken to create and spread assessment tools [2, 3, 4, 5] in order to enhance the trustworthiness and reliability of health-related websites and webmasters as well as consumers are slowly becoming aware of these tools [1]. However, some health related topics such as obesity, orthopaedic sports medicine and medical tourism are still of great concern. A great amount of commercial or consumption-oriented websites exists and studies are needed to better understand consumer behaviour toward them and their impacts on health outputs. Three of the selected papers discuss these issues and open the pathway to deeper research.

At the same time, in other topics such as diabetes in young people or family medicine, the Internet could be a great tool to empower patients (e.g. diabetes self-management) or enhance communication between patients and practitioners, if well designed and monitored. The selected studies that have examined these subjects provide interesting suggestions about possibilities that should be better capitalized. Finally, from a more general perspective, the last paper proposes an interesting methodology to understand the behaviour of health information seekers. This understanding highly contributes to enhance the ability of medical professionals to guide consumers in the selection of appropriate health-related information sources.

About the Paper Selection

The best papers selected this year discuss how the Internet is being used as a source of information and consumption in certain health-related fields. The papers determine the negative and positive impacts of the Internet as a source of information.

Nordfeldt and colleagues [10] have developed a research on the attitude of parents and young patients with diabetes I towards a Web 2.0 platform created exclusively to retrieve information on diabetes, interact with other patients and manage the disease. Lewis and colleagues [8] explore what types of information obese individuals search on the Internet, their motivations for seeking information and how they apply it in their daily lives. Lunt and colleagues [9] provide a brief overview of the most recent developments in medical tourism and examine how this is linked to the emergence of specialized Internet web sites. Freund and colleagues [7] discuss the content and quality of family medicine Web sites in Berlin, whereas Starman and colleagues [11] examine Internet-based information for commonly encountered diagnoses within orthopaedic sports medicine. Finally Eun Kyoung Yun and Hyeoun-Ae Park [6] explain the relationship between factors affecting the behaviour of consumers in Korea seeking information about their disease on the Internet by using the technology acceptance model and combining behavioural concepts with it.

Conclusion and Outlook

This review intends to highlight some aspects of online health information that are of concern because of their positive or negative impacts on consumers' health outputs. Understanding the need for attention, either to better control or to capitalize these issues more is of utmost importance.

References

1. The Harris Poll „Cyberchondriacs“ on the Rise? (August 2010) Available from: <http://www.harrisinteractive.com/vault/HI-Harris-Poll-Cyberchondriacs-2010-08-04.pdf>.
2. eEurope 2002: Quality criteria for health-related web-sites. Available from: http://www.hon.ch/HONcode/Webmasters/HON_CCE_en.htm.
3. Schembri G, Schober P. The Internet as a diagnostic aid: the patients' perspective. *Int J STD AIDS* 2009;20:231-3. doi:10.1258/ijsa.2008.008339
4. Barret L. Aspects juridiques et éthiques de la mise en ligne de données médicales nominatives et non nominatives. *Medileg*; 2009.
5. Bianchi della Porta M, Robert V. Responsabilité pénale de l'éditeur de médias en ligne participatifs. [Editors' legal responsibility for online media] *Medialex*; 2009. p. 19-25. Available from: http://bcc.ch/medias/Articles_BCCC/M B V R - A - E 6 - 2 0 0 9 - M e d i a l e x - Responsabilite_penale.pdf.
6. Yun KE, Park H-A. Consumers' disease information-seeking behaviour on the Internet in Korea. *J Clin Nurs* 2010;19:2860-8.
7. Freund T, Freund M, Mahler C, Schwantes U, Ose D, Joos S, et al. Family Practice Web Sites: New Perspectives for Patient Care and Health Information? *Fam Med* 2010;42(7):501-6.
8. Lewis S, Thomas SL, Blood RW, Castle D, Hyde J, Komesaroff PA. „I'm searching for solutions“: why are obese individuals turning to the Internet for heal and support with „being fat“? *Health Expectat* 2010 Dec. DOI: 10.1111/j.1369-7625.2010.00644.x
9. Lunt N, Hardey M, Mannion R. Nip, Tuck and Click: Medical Tourism and the Emergency of Web-Based Health Information. *Open Med Inform J* 2010 Feb 12;4:1-11.
10. Nordfeldt S, Hanberger L, Berterö C. Patient and Parent Views on a Web 2.0 Diabetes Portal – The Management Tool, the Generator and the Gatekeeper: Qualitative Study. *J Med Internet Res* 2010;12(2):e17
11. Starman JS, Gettys FK, Capo JA, Fleischli JE, Norton HJ, Karunakar MA. Quality and Content of Internet-Based Information for Ten Common Orthopaedic Sports Medicine Diagnoses. *J Bone Joint Surg Am* 2010;92:1612-8. doi:10.2106/JBJS.I.00821

Table 1 Best paper selection of articles for the IMIA Yearbook of Medical Informatics 2011 in the section 'Consumer Informatics'. The articles are listed in alphabetical order of the first author's surname.

Section
Consumer Informatics
<ul style="list-style-type: none"> ▪ Freund T, Freund M, Mahler C, Schwantes U, Ose D, Joos S, Szecsenyi J. Family Practice Web Sites: New Perspectives for Patient Care and Health Information? <i>Fam Med</i> 2010;42(7):501-6. ▪ Lewis S, Thomas SL, Blood RW, Castle D, Hyde J, Komesaroff PA. „I'm searching for solutions“: why are obese individuals turning to the Internet for heal and support with „being fat“? <i>Health Expectat</i> 2010 Dec. ▪ Lunt N, Hardey M, Mannion R. Nip, Tuck and Click: Medical Tourism and the Emergency of Web-Based Health Information. <i>Open Med Inform J</i> 2010 Feb 12;4:1-1. ▪ Nordfeldt S, Hanberger L, Berterö C. Patient and Parent Views on a Web 2.0 Diabetes Portal – The Management Tool, the Generator and the Gatekeeper: Qualitative Study. <i>J Med Internet Res</i> 2010 May 28;12(2):e17. ▪ Starman JS, Gettys FK, Capo JA, Fleischli JE, Norton HJ, Karunakar MA. Quality and Content of Internet-Based Information for Ten Common Orthopaedic Sports Medicine Diagnoses. <i>J Bone Joint Surg Am</i> 2010;92:1612-8. ▪ Yun EK, Park H-A. Consumers' disease information-seeking behaviour on the Internet in Korea. <i>J Clin Nurs</i> 2010;19(19-20):2860-8.

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Appendix: Content Summaries of Selected Best Papers for the IMIA Yearbook 2011, Section 'Consumer Informatics'*

Yun EK, Park H-A

Consumers' disease information - seeking behaviour on the Internet in Korea
J Clin Nurs 2010;19(19-20):2860-8

This study intends to explain the relationships between factors affecting consumers' disease information-seeking

behaviour on the Internet in Korea. Its aim is to help nurses understand the factors affecting consumers' use of disease-related information on the Internet. According to the authors, by assessing these factors, nurses would be able to develop an intervention programme to help patients actively participate in their communication with health providers, further increasing their compliance with care regimes in the long run.

It focused on consumers who searched disease information on the Internet, rather than healthy individuals researching health promotion or wellbeing-related information.

To explain the behaviour of consumers who research disease information on the Internet in Korea, the research team used the technology acceptance model. To this model were added basic concepts from the health belief model and health research, such as health consciousness and perceived health risk.

The results of the study showed that the technology acceptance model, along with the additions of the basic health models concepts mentioned, successfully explained consumers' disease information-seeking behaviour on the Internet. It was found that consumers' cognitive and affective characteristics, determined as initiators in health-re-

* The complete papers can be accessed in the Yearbook's full electronic version, provided that permission has been granted by the copyright holder(s).

lated behaviour, also impacted consumers' disease information-seeking behaviour on the Internet. Consumers' health consciousness, perceived health risk and Internet health information use efficacy included as antecedents in this model, were found to influence consumers' beliefs and indirectly affect attitude and intention of use. Furthermore, it was found that consumers' cognitive and affective motivations, determined as initiators in health related behaviour, also impacted consumers' disease information-seeking behaviour on the Internet. It was determined that consumers' perceived credibility was a strong determinant in forming an opinion about disease information on the Internet and intention to use.

Thus, to enhance the behaviour of consumers seeking disease-related information on the Internet, contextual quality and functional ease should be improved.

Freund T, Freund M, Mahler C, Schwantes U, Ose D, Joos S, Szecsenyi J

Family Practice Web Sites: New Perspectives for Patient Care and Health Information?

Fam Med 2010;42(7):501-6

This paper discusses the content and quality of family medicine Web sites in Berlin. The authors begin with the assumption that in Germany, health information technologies are thought to be widely implemented in family medicine practices. A pre-study determined that the distribution of family practice websites in Germany was lower than expected. Therefore the study focused on Berlin only.

Among 1,453 family practices in Berlin, only (15%) had an accessible Web site. Approximately half of all Web sites provided health information on a wide range of topics, with complementary medicine dominating. The quality of Web sites was assessed using a checklist based on commonly agreed standards based upon a review of the literature. The authors defined five distinct quality domains: legal is-

suess, transparency, timeliness, accuracy, and usability.

Most relevant results of the study show that health information was referenced in only 30% of the Web sites. Furthermore, the study revealed that sharing patient data and offering online tools for appointment scheduling or online prescription seem less common than expected. Therefore, transparency about the source and timeliness of the information and lack of barriers in the design of the website were identified by this study as the main areas where there was a need for quality improvement.

The authors conclude by suggesting that training for family physicians and residents could be useful to overcoming these problems. Indeed, they consider that in future, family medicine may use practice Web sites as an innovative approach for sharing information with patients and reorganizing the care effectively.

Lewis S, Thomas SL, Blood RW, Castle D, Hyde J, Komesaroff PA

"I'm searching for solutions": why are obese individuals turning to the Internet for health and support with "being fat"?

Health Expectat 2010 Dec

This study explores the types of information obese individuals search for on the Internet, their motivations for seeking information and how they apply it in their daily lives.

In-depth telephone interviews with an Australian community sample of 142 individuals with a BMI >30 were conducted. Data were analysed using a constant comparative method and researchers used a qualitative design, to enable participants to reflect on their experiences.

The 142 individuals were aged 19 to 75 (mean = 44), and were mainly women (n = 84). 78% searched for information about weight loss or obesity. They also searched for information about health risks associated with obesity (n = 28), how to prevent poor

health outcomes (n = 30) and for peer support forums with other obese individuals (n = 25). Participants visited a range of websites, including government-sponsored sites, community groups and weight loss companies. However, they overwhelmingly acted upon advice given by commercial diet websites. Spaces such as the Fatosphere (online fat acceptance community) provided much needed solidarity and support.

Authors refer to two key findings: 1. Individuals repeatedly searched weight loss information online in a desperate attempt to find a solution to their overweight. However, the information they found was unhelpful in achieving long-term sustainable approaches to improving their health and well-being. 2. Participants had a strong desire to connect with a community of others to share experiences, for support and accurate health information.

Researchers conclude that obese individuals are desperate to find solutions to their weight problems and to find places of support and acceptance. Their experiences should help to better tailor online support structures that help them with their specific needs and provide a safe space for them to improve their health and well-being. Consumer-driven online networks such as « Fatosphere » may be important in responding to the needs and health and social experiences of obese individuals.

Lunt N, Hardey M, Mannion R

Nip, Tuck and Click: Medical Tourism and the Emergency of Web-Based Health Information

Open Med Inform J 2010 Feb 12;4:1-1

This article provides a brief overview of the most recent developments in Medical Tourism and examines how they are linked to the emergence of specialized internet web sites. Medical Tourism takes place when individuals opt to travel overseas with the primary intention of receiving medical (usually elective surgery) treatments.

The article is structured into four sections: (1) First, it provides an overview of the growth and role of Medical Tourism in modern health care and defines the concept of „Medical tourists“ (i.e. individuals who travel overseas with the primary intention of receiving medical treatment). It identifies two types of medical tourists: consumers, who pay for the services purchased, and within the European Union citizens that ask their EU insurance to reimburse the costs of a treatment they underwent in another EU country. (2) Second, it proposes a review of Medical Tourism websites and the development of a conceptual framework to understand these; (3) Third, the paper considers broader materials pertinent to the internet and Medical Tourism and determines five policy-focused research questions (i) Who uses the sites and why? (ii) The nature of information search? (iii) The quality of information? (iv) How information influences decision-making? (v) What are the implications of the majority of sites being commercially-driven?; (4) Fourth, the paper proposes the first draft of an empirical agenda for understanding Medical Tourism and the internet.

The paper concludes with a summary and by expressing the author's wish to have established a first step towards further and deeper research on the topic.

Nordfeldt S, Hanberger L, Berterö C
Patient and Parent Views on a Web 2.0
Diabetes Portal – The Management Tool,
the Generator and the Gatekeeper:
Qualitative Study

J Med Internet Res 2010 May 28;12(2):e17

This paper explores the attitude of patients and parents toward a local Web 2.0 portal tailored for young patients with type 1 diabetes and their parents in Sweden. During the spring of 2006 the research group and two participat-

ing diabetes teams launched an Internet portal named Diabit for invited patients and parents. This portal contained specific diabetes-related information and social networking functions such as message boards and blogs.

The final participants were 16 mothers, 3 fathers, and 5 young patients (aged 11 to 18 years; average: 14 years) who each wrote an essay on their positive and negative experiences while using the portal. A qualitative content analysis was conducted on the essays as a whole.

Three main categories of attitudes were identified/constructed during the analysis and given the following names: (1) „the management tool,“ (2) „the generator,“ and (3) „the gatekeeper.“ (1) The Web Portal was perceived as a good tool for the management of the disease for young patients and their parents, as they were able to have better access to information online. (2) The portal appeared to generate more information retrieval than planned by users. (3) A factor that limited spontaneous and active use of the portal was the login requirement for access (the gatekeeper). Many negative experiences with logging onto the portal were expressed by the respondents.

This study confirms the well-known need for information related to childhood type 1 diabetes. It suggests that Web 2.0 services have great potential for supporting young patients with type 1 diabetes and their parents, improving their ability to retrieve information, with the goal of enhancing diabetes management. Such services should be carefully maintained and updated by health care professionals.

Starman JS, Gettys FK, Capo JA, Fleischli
JE, Norton HJ, Karunakar MA
Quality and Content of Internet-Based
Information for Ten Common Orthopaedic
Sports Medicine Diagnoses
J Bone Joint Surg Am 2010;92:1612-8

This study assesses the quality and content of Internet-based information for commonly encountered diagnoses within orthopaedic sports medicine.

Websites were evaluated according to their type as well as the accountability and transparency of the information (HONcode), and the information content. Information content was divided into five subcategories: disease summary, pathogenesis, diagnostics, treatment and complications, and outcomes and prognosis. Two popular search engines were used, and the top ten sites from each were independently reviewed by three authors. The data was evaluated for interobserver variability, HON scores, information content scores, and subgroup score comparison.

According to the authors, this study confirms what had been stated by other studies, i.e. information content scores were generally higher for non profit web sites, as well as for education-based web sites. There were some commercial sites with reliable information, however. The presence of the HONcode seal was associated with significantly higher HON ($p = 0.0001$) and content scores ($p = 0.002$).

Only about one-quarter of the 154 web sites reviewed displayed the HONcode compliance seal. The authors conclude by saying that it would be important to proactively urge patients to be cautious when relying on the Internet for health-related information. Patients should be advised to avoid commercial web sites, with the exception of the most reputable sites, and to look for the HONcode seal of compliance for transparency and accountability. They also consider that a similar approach to Internet use would be beneficial for orthopaedic residents and other health-care professionals who may use the Internet as a reference tool during their education.