



The Role of e-Health and Consumer Health Informatics for Evidence-Based Patient Choice in the 21st Century

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Consumer health informatics and e-health [ie, electronic health information and services available over networks such as the Internet^{1,2} and related technologies such as digital TV/WebTV, wireless media such as Web-compatible mobile phones and personal digital assistants (PDAs)] are emerging trends that will redefine health care in the 21st century. The desire of (most) consumers to assume more responsibility for their health care and a growing desire of health professionals to fully realise the potential of the patient and their families coincide with the emergence and increasing availability of interactive information accessible to consumers. These developments are further fueled by cost-saving pressures in health systems and the hope that giving consumers more information and power could increase the quality of care (eg, by avoiding unnecessary or duplicate interventions) and save costs by fully realizing the self-help potential of the patient and his family. Information technology and consumerism are synergetic forces that together promote an "information age health care system," where (ideally) consumers can use information technology to access information at home and control their own health care and thereby utilize health care resources more efficiently.³

This paper focuses on the opportunities and challenges of e-health and related developments for the concept of evidence-based patient choice (EBPC).⁴ Evidence-based patient choice is a paradigm at the intersection of evidence-based medicine (EBM) and patient-centered medicine and is one important pillar for modern health care. Patient-centered medicine and evidence-based medicine are closely linked concepts. Both emphasize that it is not the authority of the doctor that justifies a particular clinical intervention. EBM argues from the scientific standpoint that the evidence for the

intervention's effectiveness must be the foundation of selecting an intervention (emphasizing the "science" of medicine), and patient-centered medicine argues from a humanistic standpoint that patients should play a central role in decisions about health care, stressing the fact that patient preferences must be incorporated into clinical decision making.

Two requirements have to be met to enable EBPC: objective, unbiased information must be available to the patient, and the patient must have the power and opportunity to choose. While the latter depends on several factors, including the individual patient (not all patients are actually able or willing to make health-related decisions) and the physician (who sometimes fail to give patients a choice) and also the structure and organization of the health system, information and communication are the basic requirements for evidence-based patient choice rests. The remainder of this paper deals with electronic means to deliver this information and to facilitate patient choice. I will explore how the Internet changes access to information for consumers and will discuss how consumer health informatics can help to canalize the patients' demand for information to information and integrate high-quality and relevant information in the informed decision-making process.

Types of Information Needed for Informed Choice

Informed choice requires access to information about the advantages and disadvantages of all possible courses of actions, in accord with the individual's state of health and beliefs. Therefore, access to two different categories of basic information is required for patients and physician to make a shared decision:

Patient-related information refers to the individual patient and case (diagnosis, pathology, personal risk factors, etc.)

General information about the external medical evidence (for example, effectiveness of different interventions for a given disease, etc.)

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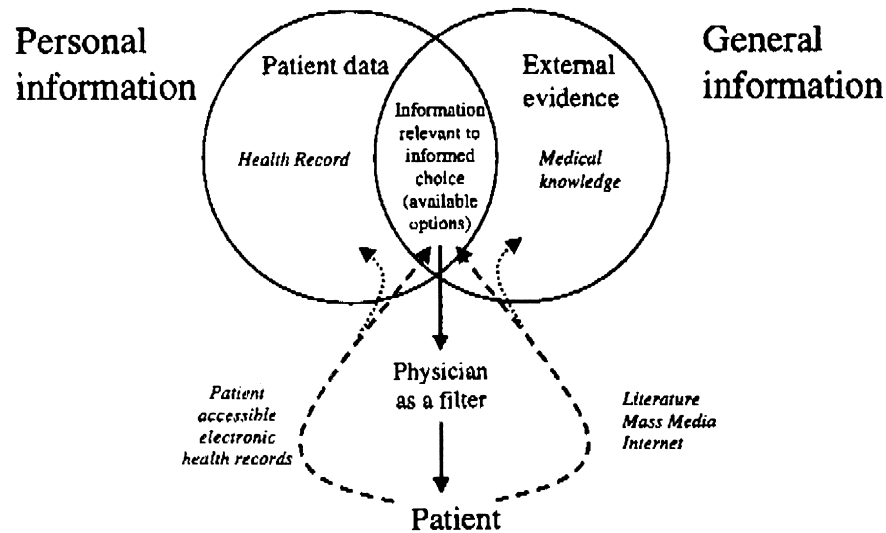


Figure 1. Patient data and external evidence are the two categories of information that need to be integrated by the physician and patient to arrive at a medical decision. Increasingly, patients can bypass the physician as a filter (and moderator), having direct access to parts of this information. This may be problematic, if this is not only information that is relevant for their informed decision process, but also low quality and irrelevant information. At the same time, this is also a chance for evidence-based medicine, as consumers are now able to question the evidence base of physicians.

It has been the traditional responsibility of the physician to integrate both types of information in the personal interaction with the patient (ie, to give patients details about their conditions and to distill and present the relevant external information on available options tailored to the patient). For example, in a shared decision-making process about a screening procedure such as a prenatal test or a cosmetic, elective surgical procedure, information about personal health risk factors have to be integrated with external evidence such as potential harm and benefits of the procedure. Ideally, physician and patient would then discuss available options and, by taking into account financial and organizational constraints as well as the individual preferences and values of the patient and physician, ideally arrive together at a “concordant”⁵ decision regarding the future management. Increasingly, however, the physician as a filter and sole provider of information is bypassed by the patient, having direct access to both the external evidence and also to his personal health record (Fig 1).

Enabling technologies (particularly the Internet) have facilitated greatly access to general health information for consumers. However, to attain evidence-based patient choice, it is not sufficient to supply the patient with information alone. The patient must also be empowered to appraise the information and must get guidance on how to integrate the information into his or her personal context. Thus, the Internet and e-health is both a chance and challenge for evidence-based patient choice. On the “chance” side, consumers have unprecedented access to information and may use

this information to challenge the decisions of their physicians. They will act as an additional instance for quality control and as a positive incitement for doctors to counteract by learning how to use electronic evidence-based resources.¹ On the “challenge” side, more information does not automatically support patient choice. Consumers may misinterpret information or may fail to arrive at the information that is relevant to them, or get lost in a stew of irrelevant and low-quality information.

An interesting perspective of e-health is that the Internet may not only allow patients to access general information, but it may also facilitate access to personal information in the electronic health record, such as the diagnosis, personal risk factors, prescribed medicines, and so on, and thus enable the personalization of information. For example, SeniorMed allows elderly patients access to their electronic medication lists via the World Wide Web. Such systems may be integrated with drug information.⁶ MedicaLogic, a company based in the United States of America, is also testing a concept called “Internet Health Record,” a service that lets patients privately access information from their real medical records over the Internet. Much as consumers do “online banking” and “online shopping” today, they will in the future be able to do “online doctoring,” browsing their electronic health records online.

Drinking from a Fire Hydrant: Internet Information

Today, consumers have possibilities to access information in abundance, through mass media, self-support

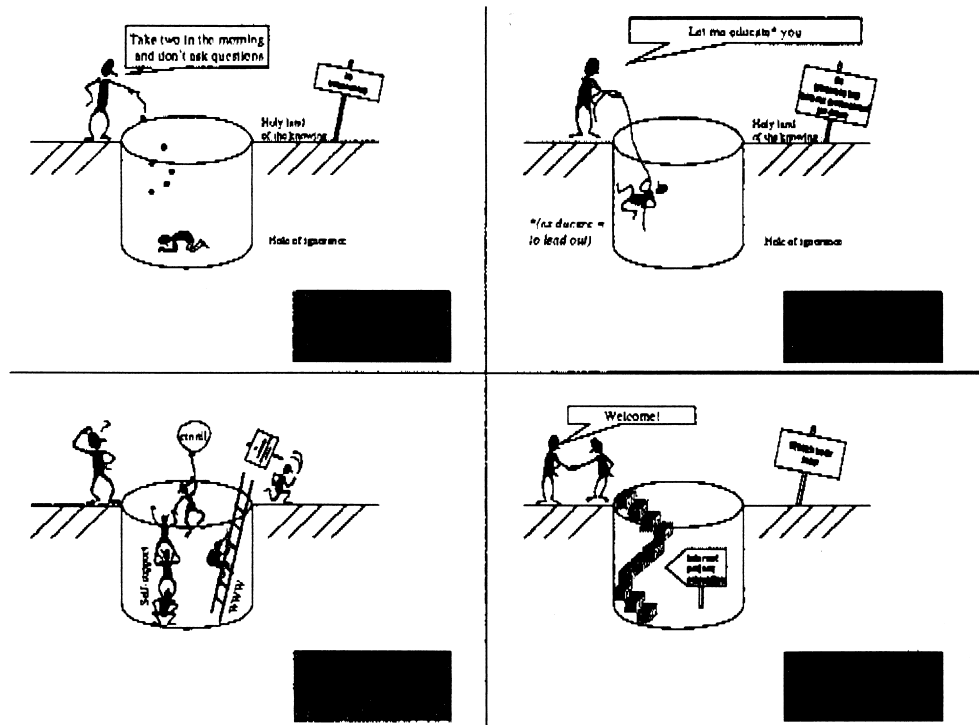


Figure 2. Different models of the consumer-professional relationship: paternalistic, educational, Internet-age, and consumer-as-partner (figure source: G. Eysenbach, Heidelberg).

groups, and particularly the Internet. The directed, intentional process of active and directed “health education” is now being complemented by an anarchical process of uncontrolled information retrieval by the patient. For the first time in the history of medicine, consumers have equal access to the knowledge bases of medicine—and they are making heavy use of this: An example for this is the fact that “the number of Medline searches performed by directly accessing the database at the National Library of Medicine increased from 7 million in 1996 to 120 million in 1997, when free public access was opened; the new searches are attributed primarily to non-physicians.”⁷ It has been argued that “a driving force behind demand for online health information is the shortage of information easily obtained from traditional channels.”⁸ With the duration of an average consultation now being down to 7 minutes in the United Kingdom (and 12 minutes in the United States of America), it comes at little surprise that physicians routinely fail to address the information needs of patients.⁹ While most physicians don’t have an understanding or access to these modern information technologies, or simply lack sufficient time to familiarize themselves with the Internet, patients have all the time in the world to search the Internet for relevant information. This new “reversed” information asymmetry creates new conflicts—the fact that patients are taking the initiative to look out for the latest research results “stands on its head the tradition in which a

doctor gives orders and the patient obeys,” as an article in the *New York Times* put it. “And that makes some doctors nervous.”¹⁰

Canalizing Information: The Role of Decision Aids and Consumer Health Informatics

The challenge is to canalize the laudable attempts of consumers to inform themselves about their conditions into positive, productive ways, so that they arrive at the health professional. On a public health level, “stairways” for the consumer should be built, guiding consumers to high-quality information. An example is Healthfinder, a government-sponsored health portal in the United States of America (www.healthfinder.gov) or the National electronic Library for Health (NeLH) in the United Kingdom.¹¹ Clearly, the demand for such information is vast.¹²

Modern computers and telecommunications will play an especially important role in reinstating the broken link between consumer and provider and facilitating access to high-quality information. According to an AHCPR report,¹³ research evidence suggests that computers may greatly support consumers in obtaining information, analyzing their unique health care needs, and helping them make decisions about their own health. A whole new academic discipline, consumer health informatics, is devoted to the exploration of the

new possibilities computers and the Internet provide for public health and health education.³

Interactive Applications

Broadly we can divide information sources (including educational tools and decision aids) into two categories:

- Noninteractive information sources (pamphlets, books, audio- and videotapes, radio, and TV)
- Interactive information sources (computer applications: interactive videodisks, CD-ROM applications, Web sites, stand-alone health kiosks)

For health educators, interactive tools are especially appealing, as (based on the assessment of user feedback) they allow tailoring of information to the needs of the individual.

Internet

Among the interactive media, the World Wide Web plays an especially important role in opening new chances to support partnership between patient and health professional, but at the same time it provides a number of challenges.^{1,2} In many aspects the Internet is different from other media, making it an ideal medium for health education and fostering active participation of patients in decision making:

- With the Internet, a huge number of people can be reached, and this reach can be combined with interactivity, allowing applications to customize information to a large audience, thereby coalescing the advantages of personal communication with the advantages of mass media, a process that is now known as “mass customization.” Thus, the World Wide Web breaks out of the “inverse communication law,” which states that the more feedback (and individual assessment) is needed, the fewer people can be reached (in other words: the more people are reached, the fewer the user involvement and effectiveness of communication).
- User feedback may not only be used to maximise effectiveness of communication on the individual level (by tailoring information), but may also be used by researchers to measure effectiveness, to refine patient information, and to do research.
- Multimedia: The Internet allows the integration of text with sound and sight; in the future, with arrival of the Next Generation Internet,¹⁴ perhaps even smell and touch.
- On the Internet, information can be pushed (broadcast) or pulled (on demand). Consumers may automatically get tailored “pushed” health messages “just in time” (for example, via email or so-called push-channels), but are also able to retrieve information as they need it (from Web sites).
- The Internet allows consumer-to-consumer commu-

nication (eg, newsgroups). This is especially important not only for exchange of information and personal experiences, but especially for emotional support (providing reassurance and helping to cope).

- Patients also enjoy the possibility to communicate with health experts under near anonymous conditions. Many patients are too embarrassed to ask questions that they think may be foolish or too personal. The Internet offers the apparent possibility to get in touch with national and international experts. Many patients simply want to have addresses and contact information of specialists for a given disease.¹²
- Another notable fact is that the Internet far surpasses other media in its ability to be “consumer centric,” thus the needs and desires of consumers are accurately and timely documented online, for example, on medical discussion newsgroups or on Web sites set up by individual patients or self-support groups. In addition to the fact that consumers can be publishers, the feedback channels (email, user statistics, online forms) allow professional publishers of health information to know what readers think, and they can react by adapting/refining their content, as changes are possible with little costs and virtually no delay. All these factors make the Internet a mirror of current consumer needs, desires, and trends and an excellent place for health professionals to study consumer needs and to understand patients concerns.

All of the mentioned advantages also have their downsides: The possibility to obtain and store feedback creates possibilities of misuse and privacy concerns, and the very fact that the Internet allows consumers to publish and exchange information without censorship and editorial control may also contribute to the quality problems.

Quality of Information

Currently, there is no agreed-upon mechanism for ensuring the accuracy, currentness, or completeness of the information that is presented to patients.¹³ This is true for both printed patient education material and patient education material on the Internet. A recent review of 54 “traditional” patient information materials concluded that “current information materials for patients omit relevant data, fail to give a balanced view of the effectiveness of different treatments, and ignore uncertainties; moreover, many information materials adopt a patronising tone—few actively promote a participative approach to decision making.”¹⁵ On the Internet, there have been numerous studies evaluating the quality of information given on different venues such as Web sites,¹⁶ newsgroups,¹⁷ and interactive venues such as email.^{18,19} While the Internet offers a huge amount of

health information, many of the authors are not trained in medicine or even health education, and mostly the intention of information provision is not to educate but to sell or to convince. While we still know very little on the impact of the Internet on public health,²⁰ the lack of reliability (accuracy) is a particular concern there. In addition to this lack of reliability, the Internet poses special problems for consumers, which have been summarized as “lack of context.”²¹ This means that the Internet poses additional problems for consumers and health professionals to assess and apply the material, compared to critical appraisal of traditional information, due to the following features of the Internet²²:

- There are no clear markers, such as traditional publishing, allowing patients to recognize:
 - the target group of a document (patients/professionals) often is not immediately apparent
 - the intention (advertisement or objective information) is often unclear
- The anonymity (of authors) makes it difficult to appraise information based on the credentials of the authors
- Internationality: information valid in foreign health care systems may not be applicable locally²³

Misinformation can lead patients with life-threatening conditions to lose trust in their provider, and take actions that undermine the effectiveness of their treatment (eg, by taking substances that interact in a negative way with prescribed medications). Patients may use their limited time with their health care provider unproductively in ways that ultimately increase costs of care, and even abandon a provider delivering high-quality care to pursue ineffective therapies. Vulnerable people may also be victimized by biased or incomplete information from those with a financial interest in the information they provide. Such risks are present in most media, but on the World Wide Web this problem reaches a new dimension.

How to Assess Quality

Appraisal of Written Material

Some quality criteria for producers of patient information have been compiled by Angela Coulter.¹⁵ A standardized quality index of consumer health information is DISCERN. The instrument is targeted at producers, health professionals, and patients to appraise written information on treatment choices. Crucial at the development was the determination of interrater agreement among different user groups. Questions with insufficient interrater agreement, such as a questions concerning design or reading level (“the information is easy to understand”), were eliminated from the final instrument. However, the validity of DISCERN in terms of the relationship between a DISCERN score and impact

of the patient information on the patient has not yet been determined. It should also be noted that the interrater reliability for DISCERN was very low when it was used by patients, thus it is not clear whether DISCERN is a truly useful instrument for consumers to distinguish good from bad patient information.

Appraisal of Internet Material

In the field of Internet publishing, many instruments to evaluate health information exist, but until now none of them have been validated²⁴: “It is unclear whether they should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm.” The Geneva-based Health on the Net foundation has compiled some consensus ethical principles for publisher of health information, the so-called HON Code of Conduct (<http://www.hon.ch/HONcode/>). Organizations that claim to have implemented these criteria display the HON logo on their Web site. However, it is not clear how many of the several thousand sites displaying the logo have actually implemented the criteria, and there is no mechanism of monitoring the sites or enforcing the principles. The HON Code principles are often misinterpreted (also in the peer-reviewed literature) as an award system, rating system, or as “quality criteria,” which would allow consumers to appraise the quality of a Web site. It is however not possible for a third party (ie, the user of a Web site) to verify, for example, that a principle such as “privacy and confidentiality” or “honesty in disclosing sources of funding” is observed.

A systematic review on different quality criteria used to assess information on the Internet has been published recently.²⁵

For use of consumers, there are now several tools available on the Internet that help users to assess the quality themselves (<http://hitiweb.mittek.org/iq/default.asp>, <http://www.discern.org.uk>, <http://www.quick.org.uk>). In the near future, a global system of accreditation or “quality seals” (evaluative meta-information assigned by trusted raters) may help consumers to identify high-quality information. An internationally recognized scheme to help the public to identify high-quality Internet sites that have been recommended or accredited by trusted medical societies or other organizations is currently being implemented in a new global project funded by the European Union called MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net—<http://www.medcertain.org>).²⁶ The aim of this project is to establish trust and improve the quality of health information on the Internet by

- Educating the public (teaching critical appraisal skills to consumers)
- Encourage self-governance and self-rating
- Evaluation and certification of information (the

project will provide a technical and organizational framework for third-party rating, so that interested medical societies and bodies can assign “quality seals” to trustworthy information)

- Enforcement (Network of Hotlines for consumers)

A trustmark (a logo showing Da Vinci’s Vitruvian man) will help consumers and professionals alike to identify high-quality information on the web.

Inverse Information Law as a Challenge

Twenty five years ago Tudor Hart described the inverse care law,²⁷ stating that “the availability of good medical care tends to vary inversely with the need for it in the population served.” In analogy the term “inverse information law”³ was recently coined, stating that the access to appropriate information is particular difficult for those who would need it most. Studies indicate that inadequate health literacy may increase the risk of hospitalization and is strongly associated with self-reported poor health.²⁸ At present, people with low health literacy do not benefit from advances in consumer health informatics and cybermedicine, as they lack access and/or understanding of these technologies. Low health literacy leads to poor health, poor health to low income, low income to impaired access to technology—thus, one fundamental problem of telemedicine and using the Internet for health education is that those who have preventable health problems and lack health insurance coverage are the least likely to have access to such technologies.²⁹

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