Education and debate

Promoting partnerships: challenges for the internet age

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The internet is transforming health care. It is creating a new conduit not only for communication but also in the access, sharing, and exchange of information among people and machines. Although it is impossible to predict its evolution, recent developments indicate that the internet will have a profound effect on the way that patients and clinicians interact. It will also foster a new level of knowledge among patients, enable them to have input into making decisions about their health care, and allow them to participate in active partnerships with many groups of decision makers such as clinicians, policymakers, and researchers.

This article describes the 10 key challenges that must be met to allow optimal partnerships to develop between patients and clinicians. This list of challenges, which is by no means comprehensive, is intended to stimulate discussion of the issues that require immediate attention to maximise the potential benefits of the internet for health care. Access to technology and information must be equitably distributed.

Summary points

The internet provides opportunities to build strong partnerships between patients and clinicians

There should be more collaboration between consumer groups and professional organisations

To be effective, information systems must be easy to access and use and must provide rapid access to appropriate information

There needs to be better integration of information and the values of the people making decisions about their healthcare needs

Collaboration between consumers and professional organisations

In the internet era it is important for patients and clinicians to work together as partners. However, there is little evidence in the peer reviewed literature that we are moving beyond the political correctness of stating these sentiments. A search of Medline, CINAHL, and Healthstar from the year of the first issue to May 1999 and of the *Cochrane Library's* first issue for 1999 using the terms "consumer *or* public *or* patient" *and* "Internet *or* WWW *or* World Wide Web *or* electronic mail" did not identify articles produced by partnerships between patients and clinicians on the use of the internet in health care. All of the studies identified were designed, conducted, and evaluated by researchers and clinicians on behalf patients, not with them.

Searching the internet for information on almost any health topic identifies many consumer and professional organisations that provide health information to the public. Few of them, however, are the result of joint efforts by patients and clinicians. One of the rare promising examples is the Cochrane Collaboration (http://hiru.mcmaster.ca/cochrane), an international organisation that encourages clinicians and consumers to work together, mainly through the internet, to design, conduct, report, disseminate, and criticise systematic reviews in all areas of health care. It would be ideal if organisations of health professionals and consumer groups viewed the development of formal links with each other as a priority in all areas of health care and used the internet to build a common platform for communication and collaboration.

Understanding how patients and clinicians use the internet

Most of the studies available on the use of the internet in health care are single surveys that target patients who already have access to the internet, patients with a specific disease, or patients seeking a particular type of health service.[1–6] Surveys of clinicians are becoming more common[7 8] but, as in other areas, their value has been limited by low response rates.[9]

To gain a better understanding of the use of the internet by clinicians and patients will require efficient, large scale initiatives to examine the factors that distinguish those people who have access to the internet, those who seek out health information on the internet, and those who use the internet as a communication tool and an aid to making decisions about their health care from those who do not. Such initiatives should generate comparative data in "real enough time" on the needs, preferences, and skills of patients and clinicians and allow interventions to be designed and implemented to foster partnerships between them.

Systems need to be easy to access and use

Few patients or clinicians receive formal training and updates on the use of information technology, and this is unlikely to change in the foreseeable future. If patients and clinicians are to take full advantage of the resources available on the internet to foster partnerships, access should be easy, affordable, and available in all settings where their interactions occur. Meeting this challenge seems increasingly feasible especially with the rapid developments in portable (especially palmtop[10]), wearable,[11] and ubiquitous (or invisible) computing.[12] Ubiquitous or invisible computing refers to the use of the hundreds of tiny devices that are so commonplace and natural to use that they become almost invisible.[13] Healthcare systems provide fertile ground for the development, use, and evaluation of this new technology.

Rapid access to information

One of the main barriers to the use of the internet in health care is that the transmission systems available to most patients and clinicians are too slow.[14] The advent of high bandwidth (or broadband) services may overcome this problem, as they will lead to internet connections that allow for the fast receipt and delivery of large amounts of data.[15] This will result in improved interactions between patients and clinicians across long distances, in the rapid exchange of information between them, and in easier implementation of applications that facilitate telepresence and telecommuting.[16] High bandwidth services will also help patients and clinicians move beyond the current text based forms of delivering health information, facilitating the use of images and sound to increase the clarity and power of messages.

Easy access to relevant, ready to use information

Regardless of how powerful, fast, or invisible technology becomes, the internet will only be valuable in promoting efficient partnerships in health care if it delivers information that is relevant, valid, engaging, and ready to apply.

Despite the impressive developments in information technology and knowledge synthesis, we are far from achieving "information nirvana."[14] The internet hosts vast amounts of information of variable quality,[17,18] coding systems are still very primitive, and we lack an effective means of improving users' critical appraisal skills.[17,19]

"I'M SORRY DOCTOR, BUT AGAIN I HAVE TO DISAGREE."

To help users cope with the information overload there should be:

- Better coding of the information on the internet and more intelligent retrieval systems[14]
- More predigested or distilled summaries of health information. Health professionals have gained considerable experience in producing and disseminating informative, evidence based abstracts of valid and ready to use research evidence.[20] Future efforts, however, should attempt to incorporate other types of information essential to the decision making process (for example, anecdotal information and "rules of thumb"),[21] make the messages more engaging, and link them with other clinical computing applications such as electronic medical records,[14] and
- Effective strategies to increase "health literacy" of the public, particularly among patients with the greatest healthcare needs.[22] The timing of these strategies will be essential. Efforts to promote better understanding of health information have focused mainly on adults. Perhaps the effectiveness of such efforts would be enhanced if they were targeted at younger learners. If children can understand health facts and basic principles of decision making, they may not only be in a better position to participate in making decisions about their health care but may require little additional health education and less reinforcement of messages about health care once they become adult patients or clinicians.[23–25]

Integrating information

Decisions about health care result from an interaction between the information available to the people making the decision, their values and preferences, and the circumstances or context in which the decisions are made.[26] Through the internet, patients and clinicians are exposed to an expanded menu of information from an unprecedented number of sources and to the values and preferences of people and groups who they do not know. We need effective strategies to help us integrate information with values and circumstances in ways that prevent an overemphasis of any one element.

Balancing virtual and face to face interactions

One of the effects of the rapid development of information technology is that many tasks can potentially be accomplished without face to face interaction between patients and clinicians. Email, for instance, can fulfil all the functions of "snail mail" and the telephone. It also allows users to participate in group discussions and to obtain and provide medical opinions.[1,6,27] Videoconferencing and high bandwidth services are creating new ways for patients and clinicians to interact and to benefit from specialist services not available locally.[15]

Accommodating changes will not be easy, given that they will require major modifications to the structure of traditional clinical practice, to models of reimbursement, and to the planning of new health services.[5] This will happen successfully only if there is strong support from healthcare planners and policymakers.

Redefining the roles of patients and clinicians

Through the internet, patients not only have access to as much information as clinicians, but they are also starting to provide advice to other patients through websites that they host and manage and email lists that they browse freely.[28] Even children can provide information to their peers, their parents, clinicians, and policymakers.[29] Some people even offer to do research on behalf of other patients for fees that surpass those charged by clinicians for consultations.[30] Patients are also seeking information actively from clinicians not involved directly in their care but who are prepared to give advice to them for a fee,[31] as part of the subscription to an internet service provider,[32] or even for free.

We know little about the way in which clinicians' roles are changing in response to the internet and to the changing role of patients. Although data are not yet available, it is evident that clinicians are finding themselves upstaged by and ill prepared to cope with patients who bring along information downloaded from the internet.[33]

We need to devote more resources to studying the implications of the internet for the role of patients and clinicians and to ensure that the clinician-patient relationship is strengthened rather than undermined.

Balancing privacy and connectivity

So far, the increased connectivity among people, computers, and organisations afforded by the internet has come at the price of less privacy, and because of the limitations of technology this is unlikely to change soon. In health care, it will be impossible to keep all of the information exchanged over the internet confidential.[34, 35] Some technological resources will maintain the same levels of privacy found in healthcare institutions and libraries, others will suffer or gain from new developments.[36] To achieve a balance between privacy and connectivity we need to concentrate on identifying aspects of the clinician-patient relationship for which privacy is essential and ensuring that they are as protected as possible. Achieving the desired level of privacy will not be enough. It is crucial that patients and clinicians feel comfortable exchanging sensitive information over the internet. The outcome of all these balancing acts will have a profound effect on innovation, regulation, and the implementation of information technology in health care.[37]

Ensuring equitable access to technology and information

Thanks to the internet, for the first time we have the conditions needed to ensure that all people have the same opportunity to access, share, and exchange information. Paradoxically, the rapid development of the internet seems to be creating widening gaps across the world.[38–40] The failure to take advantage of the internet will result in a divided world with imperfect interconnections, inequitable access, and less effective and more costly health care.

Until recently there was no clear solution in sight. New developments, however, may narrow and even eliminate the gaps. Within the next five years, for instance, there will be a large fleet of satellites (low, earth orbiting, and geostationary)[38] and solar powered aircraft with the capacity to offer affordable high bandwidth services around the world.[41] Coupled with low cost, portable, or wearable computers these innovations, and many others,[42] may lead to the development of the world's first networks providing affordable and fast access to telecommunications services to anyone, anywhere.

Conclusions

The internet will undoubtedly change the way in which we communicate, relate, learn, and think. We cannot foresee the shape or extent of the specific effects of the internet on health care. What we can see is that we are going through a rapid transition, which is full of challenges. Meeting the challenges will require, as a first step, the development of open lines of communication among industry, governments, professional and consumer groups, academic institutions, and other non-governmental organisations. Only through innovative alliances will we succeed in achieving optimal communication and access to high quality, relevant health information at the right time, in the right place, and in the right format, regardless of who we are.

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Helping patients access high quality health information

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The provision of consumer health information was pioneered in the United States: organisations such as Planetree (a not for profit, community based healthcare initiative) were among the first to provide information services.[1] Over the years several organisations in the United Kingdom—including the College of Health, the Help for Health Trust, the Health Education Authority, the Health Education Board for Scotland, and self help groups—have provided information on a wide range of health topics directly to patients or consumers. Similar initiatives have been undertaken in Europe, Canada, Australia, and New Zealand.[2] More recently, developments in Britain such as local consumer health information services, the Patient Partnership Strategy,[3] and initiatives at the King's Fund[4,5] have improved awareness of and access to evidence based consumer health information. These developments have come at a time when the amount of health information is increasing, particularly through the internet—and amid increasing concern about the varying quality of health information accessed by patients. We outline some steps to help health professionals advise patients on where to find good quality health information in this rapidly changing field.

Summary points

Patients require access to good quality, evidence based information so they can take an active part in decisions about their health care

The amount of information available to patients is increasing, particularly through the internet

The quality of this information remains variable

Health professionals need to be able to direct patients to sources of good quality consumer health information, including health related websites

Sources of consumer health information

Some of the organisations in the United Kingdom that are funded to provide health information for patients and the public are listed in box 1.

The internet

The internet offers access to health information provided by many different organisations and agencies. Several providers offer gateway services that operate a selective process, only including information that meets certain criteria. First time users may find that gateway sites are a helpful initiation to this type of information. Box 2 gives examples of widely used gateway sites that use explicit guidelines for selecting information. A fuller listing can be found in a review by Kim et al.[7] Box 3 gives examples of other well known websites that provide public access to health information. As these sites contain links to other organisations and services, including the sites of national self help groups, we have not listed addresses for individual services. These examples are limited by the dynamic nature of the web. Also, even where information is selected to conform with explicit criteria, the basis for these criteria is not always clear.

Appraisal tools for consumer health information

Assessment tools are available to judge the content of consumer health information, and many organisations have developed internal systems of appraisal. Several problems must be resolved before appraisal becomes common practice, including the resources required to