

# Consumer health informatics

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Medical informatics has expanded rapidly over the past couple of years. After decades of development of information systems designed primarily for physicians and other healthcare managers and professionals, there is an increasing interest in reaching consumers and patients directly through computers and telecommunications systems. Consumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems. Consumer informatics stands at the crossroads of other disciplines, such as nursing informatics, public health, health promotion, health education, library science, and communication science, and is perhaps the most challenging and rapidly expanding field in medical informatics; it is paving the way for health care in the information age.

## ► **Methods**

This non-exhaustive review focuses on topics from the field of consumer health informatics because there has been a markedly increased interest in this field (additional information is available on the *BMJ*'s website). Medline was searched using the terms "consumer" and "informatics." The proceedings of the American Medical Informatics Association's symposiums (1998 and 1999) and the proceedings of the ninth World Congress on Medical Informatics (Medinfo 1998) were hand searched. The AltaVista search engine was used to retrieve information from the internet, using the search string "+definition + consumer health informatics" to find unpublished reports.<sup>1-3</sup>

## ► **Health care in the information age**

Medical informatics is "the field that concerns itself with the cognitive, information processing, and communication tasks of medical practice, education, and research."<sup>4</sup> Until recently medical informatics focused on developing applications for health professionals: medical informaticians looked at medical practice mainly through the eyes of health professionals rather than through the eyes of patients. Ten years ago Greenes and Shortliffe wrote: "After many years of development of information systems to support the infrastructure of medicine, greater focus on the needs of physicians and other health care managers and professionals is occurring—to support education, decision making, communication, and many other aspects of professional activity."<sup>4</sup> This earlier orientation towards providers can also be

found in classic medical informatics textbooks, which rarely contain chapters on the information needs of consumers.<sup>5 6</sup>

### **Recent advances**

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Information technology and consumer health informatics are becoming integral parts of the modern concept of public health and national healthcare policies

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Existing systems aimed at professionals are being adapted to be used at home by patients

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Electronic health records that are accessible to patients empower consumers and can be used to tailor health information to individuals

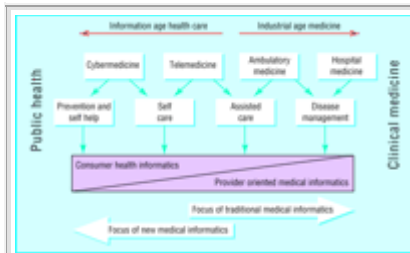
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Software designed to help users clarify their values and computer based decision aids can help patients to make informed choices and help professionals tailor interventions appropriately

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Several initiatives addressing the quality of health information on the internet are being developed, including programmes to educate consumers, encourage self labelling and self regulation of providers, and to evaluate and rate information or enforce compliance with criteria

This focus is changing. Driving factors in this change are the emergence of evidence based medicine and the growing awareness of the need to equalise relationships between health professionals and lay people.<sup>7</sup> These trends can be seen in all developed countries and are partly the result of an effort to cut healthcare costs by improving patients' abilities to help themselves and make informed choices. The increasing availability of interactive information that is accessible to consumers, most notably through the internet and related technologies such as digital television and web television, coincides with the desire of most consumers to assume more responsibility for their health and the pressures of costs on health systems, the emphasis on the health of populations and on prevention, and the growing desire of health professionals to realise the potential of patients and their families.<sup>8 9</sup> Information technology and consumerism are synergistic forces that promote an "information age healthcare system" in which consumers can, ideally, use information technology to gain access to information and control their own health care, thereby utilising healthcare resources more efficiently.<sup>10</sup> Today's "cyberdocs" on the internet may tomorrow turn into more trustworthy "cyberlicensed" professionals (who are specially trained and whose practice is monitored for quality) counselling patients online; this development is under way in the United Kingdom with the introduction of services such as NHS Direct, which provides advice to patients both on the web and over the phone.<sup>11-13</sup> Additionally, intelligent informatics applications can channel the floods of health information reaching consumers, can help patients attain a healthy balance between self reliance and seeking professional help, and can also help balance responsiveness to consumers and the management of demand,<sup>14</sup> and virtual and face to face interaction.<sup>15</sup> Information technology and consumer health informatics are becoming an integral part of modern concepts of public health and national healthcare policies in many developed countries (figure).<sup>16</sup>



The focus of traditional medical informatics is shifting from health professionals to consumers

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## ▶ Bringing medical knowledge to consumers

One challenge is to develop or adapt existing computer based decision support systems (expert systems) for use by consumers. Most of these systems were originally developed to provide advice to clinicians about diagnoses or disease management. A recent multisite, randomised controlled trial studied the effect of two decision support systems—Iliad (Applied Medical Informatics, Salt Lake City, UT) and Quick Medical Reference (University of Pittsburgh and Camdat, San Bruno, CA)—on the decision making process of medical students, medical residents, and faculty. The study showed that the magnitude of effects was related to clinical experience: inexperienced users (students) benefited more from the advice than users who had more medical experience.<sup>18</sup> These results could be extrapolated to lay people (patients) by hypothesising that such systems would provide the greatest benefit to those with the least previous knowledge (provided that the system could be adapted to their specific needs). This is a strong argument for adapting these systems for consumers.

One decision support system that is being adapted and tested for consumers is HouseCall (Applied Medical Informatics), an informatics system derived from the existing physician knowledge base Iliad.<sup>19</sup> HouseCall generates a diagnosis based on the user's symptoms and medical history, allows a personal medical history to be noted, and offers easy to read information on a variety of medical topics. Focus group evaluations of HouseCall have shown that the program is easy to use and that consumers like using technology at home to investigate health issues and like participating in solving their medical problems.

Obviously, such systems "do not and cannot replace visits with physicians; they can, however, make such encounters more productive, for both doctor and patient."<sup>3</sup> They may also help to triage patients. For consumers, the aim of such support systems would not be to make definitive diagnoses or to propose treatment but to answer simple questions such as "do I need to see a doctor?" or to alert patients to potential drug interactions or other health risks.

The main challenge in developing comprehensive systems for consumers is that little is known about how patients interact with computer based informatics tools and how they digest and act on information.

## ▶ **Electronic health records accessible to patients**

Consumer health informatics is designed to empower consumers by putting health information into their hands, including information on their own health, such as diagnoses, lab results, personal risk factors, and prescribed drugs. The European Union's data protection directive (in effect since October 1998) requires all member countries to enact legislation enabling patients to have access to their medical records.

Putting records into patients' hands is not a new idea.<sup>20</sup> Baldry et al conducted an early experiment in giving patients in the waiting room their medical records to read,<sup>21</sup> and patient held records seem to have ethical and practical benefits.<sup>22</sup>

One way of facilitating patients' access to their medical records may be through the internet or the adoption of smart cards, or both. The adoption of smart cards was recently announced by the European Union in an initiative which aims to ensure that "all European citizens should have the possibility to have a health smart card to enable secure and confidential access to networked patient information" by 2003.<sup>23</sup> Smart cards can be used as places to store health information directly, or the electronic medical record can be put onto the internet and smart cards can serve as keys by providing access. Just as consumers bank online today, they may in future be able to browse and annotate their health records online.

### **Tailoring health information to patients**

Because an electronic record provides a natural base for individually tailored health messages, online records also open new avenues for health education. On the internet it is possible to link personal information to external resources such as glossaries, websites, and databases such as Medline. For example, if the doctor's list of diagnoses or suggested changes to the patient's lifestyle contains the word "smoking," links can automatically refer the patient to health promotion sites that advise people on how to quit. Future technological advances may bring this kind of information to mobile phones, hand held computers, personal digital assistants, and wearable computers.

In a randomised controlled trial, Jones and colleagues compared the effect of tailored information for cancer patients that was based on the contents of their medical records with general information provided electronically or in leaflets; the patients preferred the tailored information.<sup>24</sup> Tailored information has also been effective in a number of other areas, including instigating changes in health behaviour or in increasing knowledge.<sup>25</sup>

In the United States, several projects are under way to evaluate the use of internet based health records that are accessible to patients. For example, a system called SeniorMed gives elderly patients access to their medication lists through the internet.<sup>26</sup> Another company, MedicaLogic ([www.medicallogic.com/](http://www.medicallogic.com/)), is also testing internet based health records ([www.98point6.com](http://www.98point6.com) and [www.aboutmyhealth.net](http://www.aboutmyhealth.net)). These records are embedded in an information system that lets users search for information on health conditions, order refills for prescriptions, and communicate with their physician's office.

## ▶ **Decision aids to support consumers' choices**

Computer based applications are being developed to help clinicians integrate a patient's preferences (values) with scientific evidence, the patient's history, and local constraints. These systems also help patients make choices for treatment or screening on the basis of their preferences for different outcomes. Such decision aids, which can be used by patients with or without healthcare professionals, are especially desirable when the optimal management strategy depends on the strength of the patient's preferences for the different health outcomes that may result from the decision.<sup>27</sup> For example, a decision system for contraceptives choice would not only take into account personal risk factors (such as smoking) to determine the best choice but also determine the values the patient places on different outcomes, such as unwanted pregnancy or venous thrombosis.

### **Consumer health informatics**

Consumer health informatics applications are designed to interact directly with the consumer, with or without the presence of healthcare professionals, and can broadly be divided into community informatics resources—such as health kiosks, community online networks and "cybermedicine" applications that anyone with a home computer can access<sup>8</sup>—and clinical informatics resources, which are provided to select groups or patients.<sup>2 17</sup>

Consumer health informatics is not restricted to the use of computers and telecommunications but also includes the delivery of information to patients through other media: the theoretical framework of consumer informatics, for example the analysis of their information needs, is independent of the media through which the information is presented. The computer is not always the most effective medium for delivering information.

It is the field in medical informatics that is concerned with

- Analysing and modelling consumer preferences, information needs, and information use;
- Developing and evaluating methods and applications to support consumers in obtaining and using health information;
- Developing and evaluating methods and applications to integrate consumer needs and preferences into information management systems in clinical practice, education, and research;
- Investigating determinants, conditions, elements, models, and processes to design, implement, and maximise the effectiveness of computerised information and telecommunication and network systems for consumers; and
- Studying the effects of these systems on public health, the patient-professional relationship, and society.

Decision aids differ from information aids mainly in that they contain explicit components to help users clarify their values: the patient's personal values and the utility or importance of the risks and benefits of each alternative are elicited. Because of their interactive nature,

computer based solutions have clear advantages over traditional media, and a number of applications already exist.<sup>1</sup> The medical informatics community is increasingly working towards integrating patients' preferences with electronic health records.<sup>28</sup>

## ▶ **Quality control of health information on the internet**

The internet is a vast resource, but to realise its full potential it is necessary to direct consumers to high quality information and to teach them how to assess the quality of information.

The quality control of health information on the internet rests on four pillars: educating the consumer, encouraging the self regulation of providers of health information, having third parties evaluate the information, and enforcing sanctions in cases of dissemination of fraudulent or harmful information.

Considerable progress has been made in all four fields. An ongoing European Union project, the MedPICS Certification and Rating of Trustworthy Health Information on the Net (medCERTAIN; [www.medpics.org/medcertain/](http://www.medpics.org/medcertain/)), is based on the idea that the quality of health information and interactive applications on the internet should not be controlled by a central body or authority but instead must be evaluated and labelled (associated with meta-information) by medical societies, professionals, or consumer organisations.<sup>29-32</sup> The project is developing a technical infrastructure to allow individuals, organisations, associations, societies, and other entities to rate the published health information found online by using a standardised vocabulary. The medCERTAIN consortium will also create different levels of certification for those who publish health information on the internet; these will range from a simple rating of "good standing" to "gold seals" indicating that the site has been externally peer reviewed.

Several groups have developed interactive internet tools to educate consumers; these tools help users to manually filter information and to assess the quality themselves ([www.quick.org.uk](http://www.quick.org.uk), [www.discern.org.uk](http://www.discern.org.uk), <http://hitiweb.mitrettek.org/>).<sup>33</sup> However, none of these tools has been validated. Discern, a tool for assessing the quality of written patient information, is being adapted for use on the internet.<sup>34</sup>

A professional code of ethics for stakeholders who have an interest in providing health resources online (such as health portals, academics, and public health experts) has been drafted. In January 2000, about 50 experts in providing health information online attended the "e-health" summit on the ethics of providing information on the internet in Washington, DC; they drew up a code of ethics that addresses issues of quality; commercial behaviour; privacy, security, and confidentiality; and the use of the internet in practising health care.<sup>35</sup>

## ▶ **Conclusion**

Although the information society offers tremendous potential for reducing the knowledge gap between professionals and patients, it also brings a risk of a widening of the gap between

those who have access to new technology and those who have been excluded.<sup>36</sup> Bridging this digital divide and bringing consumer health informatics to groups that have the greatest need will be particularly challenging. In the industrial age, the inverse care law described the idea that the availability of good medical care tends to vary inversely with the need for medical care in the population served.<sup>37</sup> In the information age, we face an analogous "inverse information law"—that is, access to appropriate information is particularly difficult for those who need it most. The vicious circle of low education and low health literacy and low income, poor health, and the inaccessibility of information technology, can only be broken if the field is not left to market forces alone but if public health policy actively brings information technology to those who are underserved.

In 1990, Shortliffe and Perrault wrote that for health professionals "it is increasingly difficult to practice modern medicine without information technologies"—a statement that is more true than ever today.<sup>5</sup> However, these days there is an additional trend: it is also increasingly unlikely that health professionals will encounter patients who have not used information technology to influence their health knowledge, health behaviour, perception of symptoms, and illness behaviour. Health professionals should, therefore, not only understand consumer health applications but also ensure that these applications are developed, applied, and evaluated properly.

The greatest contribution of consumer health informatics research to the healthcare sector may eventually be found in its attempts to systematise and codify consumers' needs, values, and preferences; in its research into how information is digested and is best presented to consumers; and in its research into how these variables influence outcome measures. Thus, current health informatics research may have greater implications for the practice of medicine than medical informatics ever did before.

## ▶ Acknowledgments

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## ▶ Footnotes

Competing interests: GE receives fees from consumer health websites for speaking and consultant work.

Additional information about the emergence of consumer informatics is available on the BMJ's website

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