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ABC of health informatics

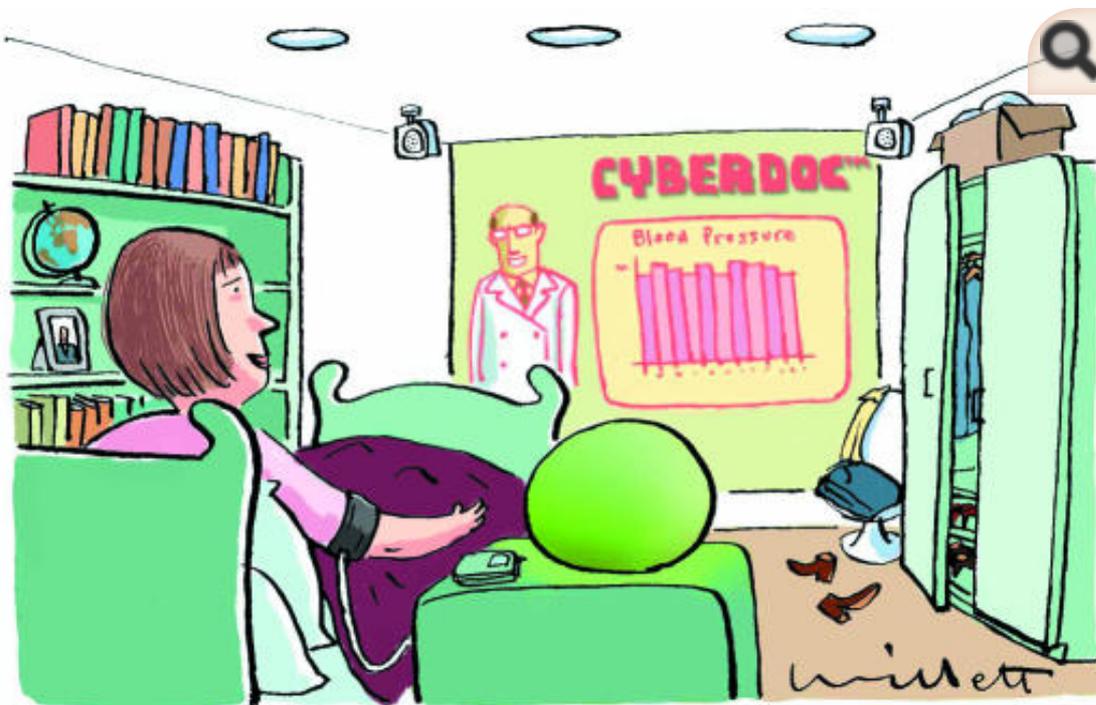
eHealth and the future: promise or peril?

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Figure 1



Despite the futuristic sound of the scenario in the box below, all the technologies mentioned are available, and some, such as computer interviewing, have been used since the 1960s.

Such a scenario raises questions about the nature of clinical practice and healthcare systems—for example, how much information and responsibility should be transferred to patients when technology allows it. This final article examines some of these issues, and ends the series where it started, with a reminder that health informatics is more about understanding people and new models of care than it is about technology.

Factors encouraging eHealth

Go to:

Gustafson and Wyatt define eHealth as “patients and the public using the internet or other electronic media to disseminate or provide access to health and lifestyle information or services.” This differs from telemedicine, in which there is a health professional at one or both ends of the communication.

Pressures towards the use of eHealth include:

- Patient demand—Information and services can be delivered in a personalised way, where and when they are wanted. eHealth provides simple, easy access to health information, support services, and goods. It can lead to loss of the general practitioner's role as mediator (for example, a

patient and specialist could email each other directly) and enhanced self expression (for example, in weblogs)

- New functions—eHealth can link previously distinct services and information. For example, all the information and forms from different government departments relevant to having a baby could be accessed from one portal
- Democracy—eHealth could allow citizens to form pressure groups, lobby for services, or even set up their own health organisations (see box at bottom of page 1392)
- Health workforce—eHealth may help deal with staff shortages or requests from staff for improved working lives (for example, working from home)
- Technology—Futuristic devices (like implanted sensors and drug delivery systems) are made possible as technology becomes more reliable, functional, and cheaper
- National policy—eHealth could help move towards services that are better coordinated, promote equity and patient independence, and adhere to government targets and lower carbon dioxide emissions (eHealth favours home based care)
- Economics—eHealth shifts some costs to the patient or community
- Safety—For example, eHealth may allow improved self management and avoidance of exposure to methicillin resistant *Staphylococcus aureus* (MRSA).

How will eHealth develop?

Go to:

In the short term, general practice and hospital websites may evolve from passive “brochure ware” (practice information and general patient advice) to active ecommerce-like applications that allow information exchange and transactions. So, general practice websites may soon cater for patients, carers, and others by providing the facilities listed on page 1392.

Table 1

Potential benefits of developments in eHealth

-
- Better information and choice for patients, carers, and others
 - Better communication of patient information to and between primary care team, leading to fewer phone calls, appointments, and improved adherence to treatment
-

- Links to external sites that have been selected for quality—for example, patient support organisations and leaflets
- A secure personal page for each patient providing access to their official medical record, including their lists of drugs, results of tests, copies of letters, and discharge summaries
- A link to NHS HealthSpace, which allows patients to construct their own “health biography, ” and enter data about long term conditions, rather than using a diary card
- Forms to book appointments or request repeat prescriptions
- A secure structured clinical enquiry form to capture patient symptoms and prompt a response from a general practitioner (GP) in the requested time.

This is the last in a series of 12 articles A glossary of terms is available at

<http://bmj.com/cgi/content/full/331/7516/566/DC1>

It is 2014 and Mrs Smith has ongoing trouble with her high blood pressure. One morning she wakes with a headache and worries that the reservoir of her implanted drug delivery system may be running down. Her bedside ambient health orb (see www.ambientdevices.com) is a reassuring green, but she turns to her video wall and asks “Cyberdoc, how are my recent blood pressure levels?” The simulated voice responds “Your records show that the drug reservoir needs a refill in three weeks time. Your telemetered blood pressure readings have been under control for the past month and today's figures are normal. Your implanted blood sugar

sensor shows normal readings too. Do you have some symptoms that you want to discuss?” Meanwhile Mrs Smith's wall graphs her recent blood pressure readings, and a list of the most common 20 symptoms affecting people of her age group in the locality. She responds, “No, don't worry. Remind me to book my repeat prescription (for a refill) in two weeks, please.”

Personal agents

Go to:

Personal agents (also known as multiagent systems) are a technology that may enable patients to retain more control over their health and personal information. A patient record agent could take care of a patient's health data and provide appropriate views only to authorised users to ensure that the integrity of the data is maintained. It would also let the patient know when data are accessed, and by whom.

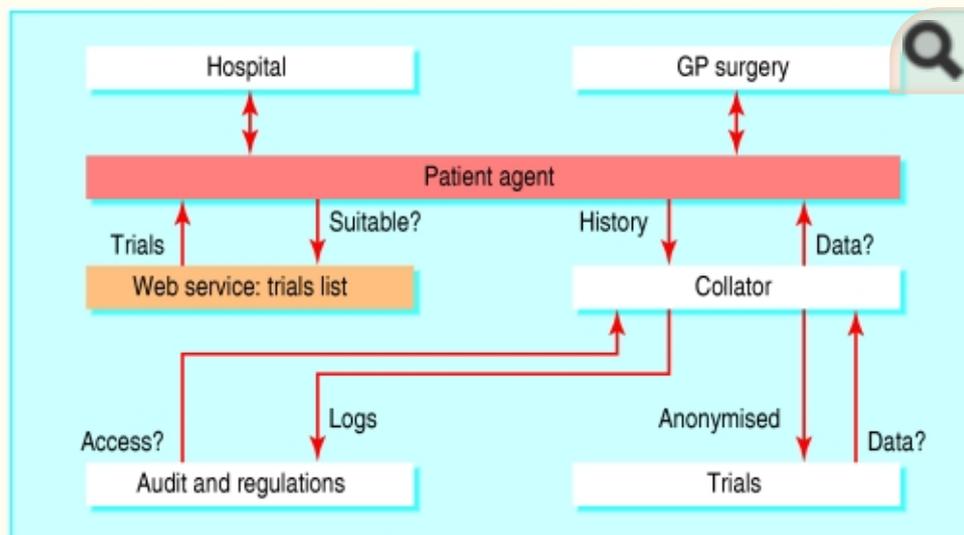


Figure 2

Personal agents could support clinical research. Patients' electronic rights could be represented and protected by their agents. Personal agents could interact on behalf of patients with electronic systems such as web services, databases, and agents representing other individuals, organisations, and functions

Patients would be able to authorise health professionals to access their data via their mobile phones, and they could receive updates through wireless technologies, such as Bluetooth. A clinical research agent could help patients who want to participate in research. The agent could find trials for which the patient would be eligible (by checking for patients' specific diagnoses, demographic characteristics, or other inclusion criteria) and notify the researcher without compromising the patient's preferences for privacy or anonymity. In such a case, it might be unclear to a patient's usual GP or specialist whether suitable research was being done, but a software agent programmed to seek out trials for which the patient is eligible opens up new possibilities._

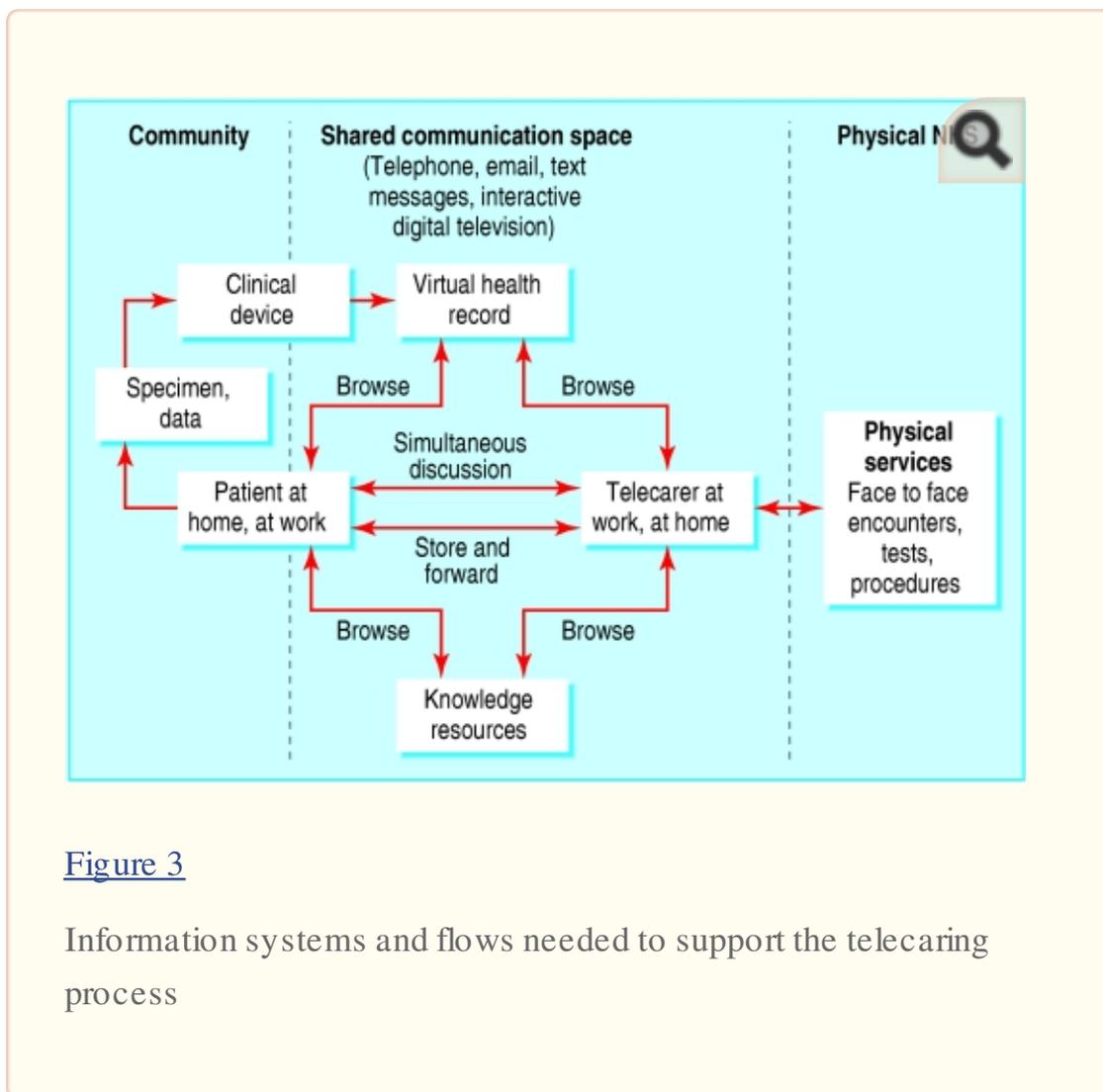


Figure 3

Information systems and flows needed to support the telecaring process

Will clinicians become telecarers?

Go to:

In the future, health professionals may move towards spending some of their working lives as telecarers. A telecarer is a health professional who delivers responsive, high quality information, services and support to remote patients or clients using the most

appropriate communication, such as telephone, email, or instant messaging. The advantages of telecare include better continuity of care for patients and telecarers being able to work from home some days of the week. Telecare also brings the need for training and new codes of practice. For example, what responsibility do telecarers have to respond to patient emails promptly, and how do they hand this responsibility over when they go off duty? One health informatics organisation has developed a code of practice for medical use of the internet. The public may even become telecarers for their friends or family, wherever they are—for example, “Dad, will you keep an eye on my diabetes while I’m clubbing in Ibiza?” This raises the question of how much responsibility and information to hand over to patients, parents, or carers. Ultimately, eHealth could allow patients with a chronic disease to club together and set up their own private healthcare organisation in exchange for data (see box opposite). The implications for the local primary care trust or chest physician need to be considered

Concerns about eHealth

Go to:

Despite its promise for some patients or clinical settings, eHealth technology may not be safe or cost effective. A “plague of pilots” (James Barlow, personal communication, 2004) have been done, but systematic reviews have shown the evidence about the cost effectiveness of eHealth and telemedicine is poor. It is not clearly understood how telephone triage services influence the use of primary care or emergency services. When triage services go online, changes in demand for health care will follow, but how will emergency and routine services be affected?

Table 2

A patient owned healthcare organisation facilitated by the internet

- Asthma patient activists bring together patient organisations and key health professionals as a foundation
 - Member patients capture and record data on activity, diet, inhaler use, peak expiratory flow rate, night waking
 - The foundation negotiates service contracts for asthma care according to national clinical guidance with GPs, the NHS, and private health providers
 - The foundation receives income or free services from health insurers, researchers, or industry in return for data
 - This raises the question: who owns patient data-the health system, doctors, or patients? Can the patient give away, sell, or exchange their data for membership of an independent healthcare foundation?
-

A personal agent is a piece of software on a computer, mobile phone, or handheld computer that represents the interests of an individual

Some health professionals are already adopting a telecaring role. They include NHDirect nurses (who respond to six million calls annually), dermatologists and psychiatrists, and GPs (who use telemedicine to answer patient email)

Purchases made on credit cards and supermarket loyalty cards could be linked with mobile phones and health records (containing a person's genetic profile) to generate individualised lifestyle advice. But when people are in the supermarket, do they want text messages warning them to avoid fatty food and cut down on alcohol?

Computers can make control of data easier because clinicians can give the encryption key to individual patients. This could allow

some people to opt out of the NHS altogether, or only make their data available to clinicians in the NHS for the duration of the consultation. To support quality improvement, health surveillance, and research activities, a compromise between the libertarian position (“it's my data and you can only use it for the period that I say”) and a free-for-all must be found.

eHealth has implications for the education, training, and supervision of health professionals. Support will be needed to become a telecarer, and organisations need to explore the implications of substituting telecare for face to face consultations. New ethical and legal issues will arise

The internet has always stood up for individuality, competition, and freedom. Surely a wider market for health services, information, and products should be welcomed? However, if the internet means that commercial suppliers can influence (or mislead) patients, or that “cyber physicians” can undercut physical primary healthcare services, whether and how to regulate eHealth must be considered.

The “cyber divide” worries many policy makers. People with lower educational achievement or income have worse health. They also make less use of the internet. If more healthcare services are shifted to new media, will health inequalities worsen? Interactive digital television is a promising way to reach these communities. The cyber divide also includes the senses—older people rarely use the telephone NHS Direct service, perhaps because of deafness. A web chat alternative has been piloted, and it was appreciated by elderly people, but it seemed too slow to roll out nationally.

Given some of these concerns, people may rise up en masse and reject the use of such technologies in health care, leading to a “Great Revulsion” (Muir Gray, personal communication, 2000), by analogy with the anti-genetically modified foods campaign (see an eHealth nightmare box above).

Summary

Go to:

The balance of benefits and risks of eHealth for individual patients and clinicians over the next two to three years is unclear. Healthcare organisations and policy makers need to consider the issues that will arise. In the long term, eHealth offers many opportunities for

prevention, choice, home based care, and chronic disease management, and it will widen access to health care for most patients. We all need to join the discussion and decide what we want for the future before others, who could be guided by commercial motives rather than quality and equity, do so.

GPs already feel the “Monday pressure” of health scares that are carried in the Sunday papers. Might rumours from the internet overwhelm the health system?

An eHealth nightmare

[Go to:](#)

Consumer choice and a plethora of commercial eHealth providers lead to multiple, fragmented patient records and supplier-dominated services. There is no single patient identifier or even disease coding system. This results in a health system that cannot access much patient data, and NHS records that hold only a fraction of what is out there. Poor or elderly people feel ever more disconnected from the high tech National eHealth Service. As a result, no National eHealth Service provider can offer a patient centred service. Health scare stories and urban myths spread across the internet like viruses with uncontained fears about privacy, safety and fragmentation of care affecting even cautious patients. Society, led by the media, starts to see technology as inhuman and eHealth becomes the scapegoat (as occurred with genetically modified foods). This leads to eHealth and electronic patient records being rejected by the middle classes, with substitution by a conservative “Holistic health service” emphasising face to face contact and individual freedom of choice-for those who can afford it.

Acknowledgement: Muir Gray

Notes

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The series will be published as a book by Blackwell Publishing in spring 2006.

Competing interests: None declared.

Further reading and resources

[Go to:](#)

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