Information in practice



National electronic Library for Health (NeLH)

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BMJ 1999;319:1476-9

Modern healthcare professionals have to resolve the information paradox; they are overwhelmed with information but cannot find particular information when and where they need it.1 The internet and its associated technologies, especially the world wide web, have the potential to both exacerbate and reduce these problems. Simply providing access to the world wide web per se may exacerbate the problems of information overload, since every web browser has access to hundreds of millions of pages of information. However, the cost effective provision of access to timely, current, and high quality information is what internet technology potentially offers. Creation of the National electronic Library for Health (NeLH) should be seen as an attempt to harness internet technologies to solve this information paradox.

Sir Edward Waine, regius professor of medicine in Glasgow, who invented Waine's thyroid index, an early, pre-computer, decision support system, used to teach about "la maladie du petit papier." This described the patient who, somewhat nervously, took a little bit of paper out of his jacket pocket towards the end of the consultation and used this paper to remind him of the questions that he knew he was bound to forget in the stress of the consultation. Many clinicians have now found that le maladie du petit papier is now but a fond memory as they face daily "la maladie du grand printout," an altogether more daunting challenge. The world wide web has blown away the walls and doors of medical libraries, which once shielded medical knowledge from the public gaze. Members of the public can now have access to almost all the information that professionals have.

Internet tools

Internet technologies potentially provide the tools to solve the knowledge paradox. At the most basic level,

Key internet tools to be used within the NeLH

Web browser—Used to view the internet from a PC Hypertext—Link between documents by a single mouse click

Search engines—Find information within a single or across multiple internet sites

Alerts-Email you automatically about new items Personalisation—Allows creation of a customised website to meet your needs

Summary points

Healthcare professionals face a paradox; they are overwhelmed with information but cannot find a particular piece of information when and where they need it

Creation of the National electronic Library for Health (NeLH) is an attempt to harness internet technologies to solve this information paradox

The aim of the NeLH is to provide easy access to best current knowledge to improve health and health care, patient choice, and clinical practice

Key internet tools to be used in the NeLH include a web browser to view the internet, hypertext links between documents, search engines to find information, alerts to warn users automatically about new information, and personalisation to allow users to customise the website to suit their needs

The metaphorical architecture of the NeLH will comprise an atrium with help desks and virtual branch libraries, know how (guidelines and audit), knowledge (best current evidence), NHS Direct Online (information for patients), and knowledge management (training in better presentation and use of knowledge)

the web browser and hypertext link provide easy to use tools to view documents and to move between them. Hypertext links allow rapid movement from document to document in a way that is not possible with printed material. This hopping from place to place—known as "surfing the web"—is often enjoyable but can also be frustrating and time consuming.

Search engines go some of the way towards targeting the information that you require. A search engine can either search a single site or search across many. It can be constructed so that it either searches comprehensively or across a limited range of knowledge sources. The "EBM search" located on the Doctors Desk home page² is an example of the latter: a simple search term produces a small number of hits. The aim of this search engine (created by Dr Adrian Brown, St George's Hospital Medical School, London)

is to produce the right volume of review articles for a busy general practitioner who does not have the time for a more extensive literature review. EBM search can also be launched from within a general practice clinical computer system, which means that once a diagnosis has been entered on the computer the search engine can be launched. This approach will help ensure that the target times of 15 seconds for accessing knowledge will be met.

User definable alerts can ensure that you receive an email whenever a journal article is published on a subject you are interested in. The *BMJ* website offers this facility to users (www.bmj.com).

Lastly, a range of commercial products allow personalisation. These are usually referred to with the "my" prefix. The "my Yahoo" internet page³ is a good example of how personalisation interfaces currently operate.

NHS information strategy

At the end of 1998 the new information strategy *Information for Health* was published, the culmination of an intensive project led by Frank Burns.⁴ The information strategy is wide ranging but has one simple central message, that investment in computing should benefit clinicians and patients—a radical departure from previous strategies, which have focused on the financial and managerial benefits of investment in information systems. Part of this strategy was a proposal that there should be a National electronic Library for Health.⁵

Aim of the National electronic Library for Health

The NeLH mission

- To provide easy access to best current knowledge
- To improve health and health care, patient choice, and clinical practice

The mission of the NeLH is to deliver information to improve patient care. Obviously, knowledge alone will not achieve these objectives, but without easy access to good knowledge decision makers face an impossible barrier to providing high quality health care.

The NeLH will be developed on the following principles:

- It will be obsessed with the quality and not simply the quantity of the information
- It will contain both "know how" and knowledge
- It will be equally open to patients and clinicians, to the public and managers
- It will exist only in electronic form; there will never be a building called the NeLH
- It will involve its users in decision making as well as delivering a service to them.

The knowledge links to the site will be comprehensive, but its search engines will retrieve data only from sites that have met quality criteria.

Metaphorical architecture of the NeLH

Architecture of the National electronic Library for Health

- · Atrium with help desks and virtual branch libraries
- Know how-guidelines and audit
- Knowledge
- NHS Direct Online—patient information
- · Knowledge management

The atrium

New entrants to the library will have access to a number of help desks, these will either be for discrete groups of users (such as for occupational therapists or orthopaedic surgeons) or to aid use of specific tools (such as Medline or the Cochrane database). The library is planned as a multidisciplinary source of knowledge and know how, but it is recognised that each professional group will have its own needs. It is envisaged that royal colleges and societies will become "cybersocieties," delivering services to all members electronically; the Royal College of Surgeons of Edinburgh has already gone some way down this road.⁶

Help desks are fine, but they imply a hierarchical relationship, with helpers dispensing knowledge to those seeking help. One fact that has emerged from the rapid evolution of the world wide web is that its ability to connect people is at least as important as its ability to connect facts. The web businesses that flourish are those which people find sociable; discussion groups, although they can be irritating, have transformed academic and social life. Facilitating the development of "knowledge cafes" will be a core area for NeLH.

Such contacts are already an important sources of information for many patients. Sandvik has described how the internet can be used, both via personal communication and access to health information, to help treat urinary incontinence.⁸

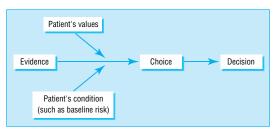
Know how

In future more care can be managed through the development of healthcare systems with guidelines and audit. We are entering an era when guidelines will proliferate and the number of effective computer decision support systems will increase. One of the missions of the National Institute of Clinical Excellence (NICE) will be to introduce order into this rapidly growing subject, and the NeLH will look to NICE as a key supplier of know how. Prominence will be given within the NeLH site and its search engines to material from NICE. It may also remain a mandatory part of any personalised interface that a user develops with the library.

Know how is also transmitted through education, and the NeLH will act as a focus for online education.

Knowledge

The need for decisions to be based on best current knowledge is now unquestioned. Those who have questioned it perhaps did so because they were unclear about the part that knowledge played in decision-making. The figure shows the model on which the NeLH is based, illustrating that knowledge always has to take into account the patient's condition and the



Model for decision making

patient's values, or, in the case of decisions about groups or populations, the needs and values of that particular population.

Of central importance in the provision of knowledge in the NeLH will be its quality assurance system, and for this the NeLH will look to the Department of Health's research and development programme¹⁰ for advice on which knowledge to supply for the knowledge platform.

NeLH knowledge platform

Researchers collect data and produce information, but for many users the information that is published in scientific journals, written primarily for other researchers, is not particularly helpful: it is often biased, 11 with the bias being very difficult to detect, 12 and the quality of the information may be difficult to discern and may not be expressed in the way that is most useful to users. For example, results may be presented as relative risks only, whereas many users would also like to know absolute risk and benefit. The NeLH will therefore give priority to systematic reviews of knowledge that are regularly updated, such as the Cochrane Database of Systematic Reviews. 13

NHS Direct Online

Informed patients will be a major driving force for change in the 21st century. Although the main impact of the world wide web at present is to make patients amply informed, the aim of the NeLH is to ensure that they are not only informed but also well informed through NHS Direct Online, which will complement the telephone service NHS Direct.¹⁴

These information sources will have to compete on the web with all the other sources of information, some good and some bad, and will rely on the continuing confidence that the public has in the NHS. The public also still has faith in the advice of clinical professionals, particularly doctors, and it is therefore essential for the NeLH to provide the same message to clinicians and patients and ensure that both are centrally involved in its development.

In the short term the aim of NHS Direct Online will be to provide patients with information to help them address three questions:

- How can I stay healthy, feel better, and reduce the risk of disease?
 - Do I need to see a doctor for this problem?
- How can I learn more about my condition, contribute to my care, and make the best use of health services?

Knowledge management

Hitherto, libraries have been knowledge warehouses. Even if library users restricted their choice to secondary publications and distilled knowledge they would still be overwhelmed by information. Knowledge management can help mitigate this problem through better training of users and better presentation of knowledge.

The NeLH will also take up the work developed by the Department of Health's research and development programme to promote better knowledge management. This will occur through the development of the skills and resources to produce, distribute, find, appraise, and use knowledge. The main groups who will benefit from the knowledge management facilities are:

- Doers of research
- Users of research—patients, clinicians, and managers
- Teachers and trainers of healthcare professionals
- Librarians and information specialists.

Access to the NeLH

Standards have been set for access to information in the NeLH in different circumstances (see table). However, accessibility has other challenges: an NHS that operates throughout the day needs a 24 hour knowledge service, and much study and most accessing of medical internet information happens from home. The NeLH must meet these needs.

The final issue of access relates to locality. This can mean different things to different people, and the architecture of the NeLH must take account of this. National guidelines require local adaptation if they are to used effectively, and the construction of NeLH must facilitate this process while making the local changes explicit. An open architecture that will allow the linking of knowledge to patients' medical records is also a vital long term issue.

Virtual branch libraries

Branch libraries flourish because they are close to communities—provided, of course, that they meet the needs of the community. Three different but related types of virtual branch libraries are planned for the NeLH:

- Clinical branch libraries will be primarily for patients and clinicians and relate to a specialist subject in medicine
- Complementary branch libraries will focus on populations

Hierarchy of presentation of research findings		
When knowledge is needed	How quickly?	What?
Speaking with a patient (such as in consultation or on ward round)	Within 15 seconds	"Bottom line" that can be reached within 15 seconds
Reflecting on a patient (such as over coffee when discussing a case with colleagues or when writing to a colleague)	Within two minutes	Structured summary of article, systematic review, or guideline that can be read in five minutes or less
During training or professional development	Within a week	Full text linked to other relevant material or open educational resources, allowing users to read as much as they want, usually at home, either for research or continuing professional development

 Health improvement libraries are designed to meet the needs of those who make decisions about groups of patients or whole populations.

Conclusions

The NeLH must be seen in the context of the global information society. Nationally, the Department of Health's commitment to public information and involvement is reflected in the Centre for Health Information Quality.¹⁷ There is unprecedented investment in training and development in the public library service—now called the People's Network.¹⁸—and there is considerable investment in education and the National Grid for Learning.¹⁹ Health is not a single sector issue, and the NeLH will integrate with these initiatives. Many stable building blocks are already in place in the medical arena, from the Cochrane Collaboration to the *BMJ*'s web presence.

Few countries have a better healthcare library service than Britain, but there is no room for complacency. The plan for the NeLH envisages that existing libraries will become part of the NeLH as soon as they are connected to the web and the NHSnet. Their most valuable resource, the librarians, will play a central part in the development and delivery of the NeLH's aims and objectives. The NeLH is fortunate in being able to learn from and work with other important institutions, notably the National Library of Medicine. The NeLH will have no large building-it will be a virtual library, and its users will also be involved in its construction in a way that would be impossible if it were built of bricks and mortar. The NeLH will be a virtual organisation, connecting both sources of knowledge and users, who are all too often too isolated; were it to have a motto, it would be difficult to better E M Forster's oft quoted "Only connect."

Competing interests: Both authors have academic sessions funded by the NHS Information Authority, the funding body of the Net H

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(Accepted 13 October 1999)

Instant wisdom

This is the first paragraph of a lecture I gave to the Cardiff Medical Society on "Decision making in the glare of publicity." An abridged version was published in *The Scientific Proceedings of the Cardiff Medical Society* on 8 January 1974.

"When I was a student at University College Hospital, London, I was deeply impressed by a story which Thomas Lewis recounted of his early years in London before the first world war. As a young man he was invited to dinner one evening by Sir James Mackenzie, the then doyen of London cardiologists. The company, all medical men and their wives, was a distinguished one and Lewis far the most junior person present. It was Edwardian England and before the port circulated the ladies retired. At this stage one of the elderly physicians enquired of Mackenzie how his two daughters were. Mackenzie replied that one of them was poorly and he thanked the questioner because it reminded him that he had intended to seek the opinion of his guests on a peculiar patch of oedema which had appeared on the girl's forehead. A message was sent to the nursery and the young lady, about twelve years old, was brought down. The rash was examined. Eventually one of the patriarchs pronounced. It was clearly angioneurotic oedema, Quincke's circumscribed oedema. All were satisfied: a diagnosis had been made—the young lady was taken upstairs. The next day she died. She had an abscess of the frontal lobe of the brain. Lewis told the story to show us students that giving a name to lesions may satisfy professional dignity but does not necessarily help the patient. He used to add, however, that medicine was a difficult subject and diagnosis was not made easier if the patient was the daughter of a distinguished physician, the consultation took place while the port circulated and was in the presence of a number of respected colleagues. It was Lewis's opinion that if any of the gentlemen present had seen that girl earlier in the day in an ordinary outpatient clinic they would have done better than merely describe the lesion in Latin."

 $\label{thm:continuous} Owen\ L\ Wade\ \textit{former professor of the rapeutics and clinical pharmacology, Birmingham}$

We welcome articles of up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.