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ENABLING THE EXPERT ERA

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ABSTRACT

At the turn of the century we are entering a new era – the expert era. In the old era (the twentieth century) our concept of expertise was associated with qualified professionals. The highest quality, best funded library and information services were those for clinicians and focused on supporting this professional expertise and mystique. Major social changes have now called into question our understanding of where expertise lies. The shift in the burden of illness from acute to chronic conditions has created a generation of people living with long-term illness and disability (expert patients). At the same time revolutionary developments in information and communications technologies are opening up to patients and the public information sources which were once the exclusive preserve of professionals. Where once we thought of a divide between patient and professional information needs a more valid distinction is between expert users (who live or work with a health issue on a daily basis) and occasional users (who may have only episodic information needs on the topic). The paper will consider how library and information professionals can enable the expert era through development of universal access to key information sources. In the UK the government is committed to establishment, by April 2003, of an integrated National Knowledge Service meeting the needs of patients and professionals for the same high quality knowledge to support health care.

INTRODUCTION

At the turn of the century we are entering a new era – the expert era. In the old era (the twentieth century) expertise was seen as the preserve of highly qualified doctors and other health professionals. Major social changes have now called into question our understanding of where expertise lies. The shift in the burden of illness from acute to chronic conditions has created a generation of people living with long-term illness and disability (expert patients). At the same time revolutionary developments in information and communications technologies are opening up to patients and the public information sources which were once the exclusive domain of professionals.

TWENTY FIRST CENTURY HEALTH CARE

Earlier this year the UK Chancellor of the Exchequer committed significant additional funding to the National Health Service. The Chancellor also commissioned a leading banker, Derek Wanless, to produce a report on how the new funding might most effectively be spent (1).

Wanless identified the following key drivers for twenty first century health care:

- Patients want more choice and higher quality services
- An ageing population and chronic disease management is driving up health costs
- Information and communication technologies have considerable potential for improving delivery and quality of care
- There will be major changes in the ways in which health professionals work

Wanless sees particular value in investing in support for self care. A twenty first century health service can support self care by enhancing people's independence and expertise through investment in information, skills and technology. The report suggests that by 2020 visits to family doctors could decrease by 40% and visits to hospital outpatient departments by 17% due to increased self care, both for everyday health problems and chronic illnesses. For every £100 spent on encouraging self care around £150 of benefit could be delivered in return.

THE EXPERT PATIENT

In the UK at any one time as many as 17 million adults are living with a chronic illness (heart disease, arthritis, diabetes, asthma, epilepsy, mental health problems etc.). People have information needs specific to their individual illness but there is also a core of common needs:

- Recognising and acting on symptoms
- Dealing with acute attacks
- Making most effective use of medicines and treatment
- Accessing social care and other services

Patients live with chronic illness every hour of the day, every day of their lives. They acquire considerable personal expertise and doctors often observe "My patient understands their disease much better than I do". (2) Recognising that the knowledge and expertise held by the patient has for too long been an untapped resource the Department of Health has now developed an Expert Patients Programme (3) aimed at improving knowledge, skills and confidence so that patients can take effective control of their own lives.

SHIFTING THE INFORMATION FAULTLINES

Rapidly increasing access to information and communication technologies (ICTs) has been one of the most significant social revolutions of the past ten years. Current estimates suggest that worldwide over 500 million people have made use of the Internet (4). Latest figures show that in the quarter ending May 2002 43% of UK homes were connected to the Internet (a figure which has risen from only 10% in 1999) with average time online 8 to 9 hours per week (5). In addition to this of course many people access the Internet at work, college or public terminals. Accessing health information is one of the commonest reasons for going online : surveys suggest that up to 75% of all web users have used it to access health information, and those that do so access health information 3 times a month (6).

The web revolution has undoubtedly narrowed the old information divide between professionals and patients. In principle anyone can access most forms of knowledge – and anyone can publish, quickly, cheaply and with potentially very wide readership. Developments in information and communications technologies are opening up to patients and the public information sources which were once the exclusive preserve of professionals. At the same time patients and carers are able to share their knowledge and experience with others, wherever they may be in the world.

Where once we thought of a divide between patient and professional information needs a more valid distinction is between expert users (who live or work with a health issue on a daily basis) and occasional users (who may have only episodic information needs on the topic). But despite this shift new fault lines have been created. It would be wrong to assume we are all experts now and significant disadvantage remains around:

- Poverty of access
- Poverty of understanding

POVERTY OF ACCESS

While on the one hand technological advances have been a force for information equality between patients and professionals, on the other there is concern that new technologies may further exacerbate health and social inequalities. The “digital divide” may exclude the poor, the homeless, refugees, people from ethnic minorities, people who are illiterate, disabled or elderly – exactly those groups who may have the greatest health needs and unequal access to health services.

Figures from the UK (7) confirm that Internet users tend to be young (48% under 35, only 11% over 55), affluent and employed. Only 16% of those aged over 65 have access to the Internet and there are regional variations with more people in the affluent South of the country using computers compared with the more socially deprived North and Midlands.

POVERTY OF UNDERSTANDING

Decreasing the digital divide is not, however, simply a question of providing greater access to more information. To be real experts people also need the tools and skills to make best use of information. There is no doubt that health information on the

Internet is of very varying quality. Health professionals have their subject knowledge and often training in critical appraisal skills to help them sift the good information from the bad. Although there are now a number of programmes teaching critical appraisal skills to patients and consumer representatives, members of the public often do not have this expertise.

As a result a number of initiatives have been developed to identify quality criteria which can be used by professionals and lay people alike to assess the quality of health websites. These tend to have three main approaches:

- Codes of conduct or ethics
- Systems of accreditation
- Evaluation tools

Quality of health information on the Internet has been the subject of a number of recent articles (8) including a recent theme issue of the *British Medical Journal* (9).

EQUAL PARTNERS IN SHARED DECISION MAKING

Despite these concerns, there is no doubt that the dramatically increased accessibility of information to both patients and professionals has the potential to demystify medicine and create a more equal relationship. Both patient and clinician bring expertise to the partnership. The patient understands better than anyone the experience of living with the condition, both from their own experience and that shared with others through self help groups, online communities etc. The clinician has considerable technical expertise and knowledge but is no longer the sole provider of knowledge or care. Instead their role will increasingly be to help patients navigate their way through complex and often contradictory information and to help patients to assess risk and benefits which are meaningful to them (10). Creating a more equal partnership is about more than simply sharing information and improving communication. A true partnership of equal experts means sharing not only information, but also sharing responsibility and decision making. As the *BMJ* (11,12) has observed “shared decision making may be the most important change in medicine in the next decade”.

MEETING PATIENT & PUBLIC INFORMATION NEEDS THROUGH NHS DIRECT

Over the past 25 years considerable library and information resources have been developed for health care staff. Professionally managed library and information services are available in most health care organisations with major national investment. More recently attention has shifted to meeting the information needs of patients and carers, particularly through the NHS Direct service.

NHS Direct

NHS Direct provides 24 hour access to nurse advice and health information throughout England and Wales. NHS Direct was launched as three pilot sites in March 1998 and has since expanded to 22 call centres. NHS Direct now handles around 120,000 calls each week and has handled in excess of 10 million calls in total. NHS Direct has become the largest provider of telephone based healthcare of its kind anywhere in the world.

From the outset, NHS Direct recognised the contribution that clinical decision support systems – software systems that help nurses in their assessment of patients – could make in ensuring a consistently safe service. At the piloting stage, a variety of clinical decision support systems were used. However, from October 2001, all 22 NHS Direct call centres have been using the same system, the NHS Clinical Assessment System.

Having common software systems across all 22 call centres will allow NHS Direct to make best use of its capacity by networking the individual centres so that they may operate as one virtual contact centre. Virtual contact centre technology allows NHS Direct to move calls around sites to ensure the best fit between demand and capacity; handle service or system failure in individual call centres; recruit in geographic areas where it is easiest to recruit staff; and close individual centres for training, staff development, or systems maintenance.

NHS Direct Online

Following the establishment of the first NHS Direct telephone call centres, the service moved promptly towards the development of an NHS Direct website. NHS Direct Online was launched by the Prime Minister in December 1999 and has established itself as one of the UK's top public sector websites. In March 2002 NHS Direct Online was awarded the "Best e-Service Website" at the Government Internet Forum Awards. NHS Direct Online currently receives over 7 million hits per month from 250,000 unique visits.

The most important new service development for NHS Direct Online over the past year has been the launch of a new online health information enquiry service, which enables patients and the public to submit enquiries to the website if they can't find the health information they're looking for. Requests for information are submitted via an enquiry form on the website with the response posted on a secure web server for collection by the enquirer, who receives an email notifying them that their information is ready. Enquiries are researched by a team of skilled library and information professionals and answered within five days. A recent review in the UK consumer magazine *Which* (13) described the online enquiry service as "the jewel of the site"

Multi-channel access

In addition to the NHS Direct telephone service and website, public access to health information is also available via NHS Direct Information Points (touch screen kiosks), NHS digital tv pilots, and in print (14). Nearly 200 Information Points are now in place in NHS walk in centres, shopping centres, libraries etc. with an *NHS Plan* commitment to have 500 installed by 2004. NHS Direct Information Points provide access to NHS Direct Online information for people who do not have access to the internet at home or work.

During 2001-2 NHS digital tv pilots have been running in several parts of the UK. The pilots, which are currently being independently evaluated, provide access to NHS Direct Online content, which has been redesigned for the digital tv medium, as well as to specially commissioned programming on health topics. The largest of the pilots, Living Health in Birmingham, also provides a GP appointment booking facility and, through the NHS Direct In Vision initiative, allows users to see the NHS Direct nurse on screen when contacting the West Midlands call centre.

Not forgetting that for many people print is still the most accessible and familiar medium, information on coping with common health problems at home is also available in the *NHS Direct Self Help Guide* which is now in its second edition. The objective of NHS Direct's multi-channel approach is to give users choice in the medium which is most accessible and comfortable for them, with the assurance of consistent quality of information and advice whichever channel they choose.

JOINING UP AND GETTING PERSONAL

In the last five years we have seen information services for patients and the public in the UK develop to a scale similar to those available for professionals. But there is still much to do. Next steps are likely to see:

- Increased personalisation of information
- New technologies to increase access and inclusion
- Integration of services for professionals and patients

Personalisation

During the year ahead the NHS Direct online enquiry service will be developed further to include nurse advice on clinical symptoms through a webmail environment for those who would find this a convenient and accessible route. An individual Healthspace which users can populate with their own personal health information and information will be provided as an option on NHS Direct Online. This will in time build into a confidential and secure web based health record that the patient can consent to share with others in the healthcare process.

Technologies

Early findings from the NHS digital tv pilots suggest that digital tv has considerable potential for increasing access to health information for those who have traditionally been socially excluded – including poor people, older people and people from minority ethnic groups. Take up amongst these groups was higher than might have been expected and health information proved a popular application. We are expecting a major new programme of work to present health information and transactions via digital tv platforms from 2003.

Integrating services

Close working between NHS Direct Online and the National electronic Library for Health has been built on the shared principle that both partners in the healthcare process may require access to different levels of information at different stages – and will wish to move easily and quickly between the two.

Development of a fully integrated National Knowledge Service is now policy in the UK. The government's response to the inquiry into children's heart surgery at Bristol Royal Infirmary (15) stated:

"We are creating a new National Knowledge Service for the NHS which will meet the needs of professionals, patients and the public for up to date, evidence based information by fully integrating the development of NHS knowledge systems"

With *Learning from Bristol* we have finally moved on from the concept of separate information services for patients and professionals to an acceptance of the need for integrated services for equal partners, equal experts.

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