Medicine and the Internet, Third Edition

Bruce C. McKenzie
Editor

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Third Edition

EDITED BY

Bruce C. McKenzie

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Preface

During the closing years of the twentieth century the Internet had become virtually ubiquitous, insinuating its way into almost every facet of life. The changes it has brought about have been hailed as both beneficial and threatening. In either case, further changes are inevitable. Medicine is certainly no stranger to change and, like the Internet, is undergoing perpetual development. The doctors of today are more accountable. They must be visibly efficient in their communications, and able to access current information to support evidence-based practice. The need for continuing professional education drives some to seek new ways of learning online. Technological solutions play an ever-increasing part in their working lives.

The Internet in particular has a growing role in addressing the changing communication and information needs of health professionals and their patients. The exploration of its value as a tool in everyday health care is as exciting as it is challenging. To keep pace with these changes a book such as this must periodically reinvent itself. This edition—like those before it—aspires to serve as your guide to making the Internet work for you as a healthcare professional. Itself the product of changing needs, this book has a tighter focus than previous editions. It leaves behind some of the more obscure detail concerning general computing and telecommunications, simultaneously building on the strengths of previous editions—attention to detail, clear explanations of terminology, practical advice, and the elucidation of topics of particular importance to those delivering health care.

This third edition also includes more contributed chapters. Just as the generalist consults a specialist in clinical practice, knowledge and opinion about medical use of the Internet has grown to the point where expert help is prerequisite to a deeper understanding of the issues. We trust our combined experience and enthusiasm will deliver a book that is both relevant and unique. We aim to provide the reader with the necessary knowledge and confidence to begin exploring and using the medical Internet on his or her own. As the original and foremost UK-focused book offering comprehensive discussion of the issues relating specifically to medical use of the Internet, we welcome your comments and suggestions to ensure this book remains pertinent and accurate. Please feel free to contact us at medicine.books@oup.co.uk.

October 2001 B.M.

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Contributors

Volume editor

Bruce C. McKenzie MB ChB MRCGP
General Practitioner
Chesterfield, UK

Contributors

Richard J. Appleyard PhD BA(Oxon)
Assistant Professor, Information Technology Group, Oregon Health Sciences University, Portland OR, USA

Andrew Booth BA MSc Dip Lib ALA
Senior Lecturer in Evidence Based Health Care Information and Director of Information Resources, School of Health and Related Research, University of Sheffield, Sheffield, UK

Harry Brown MB ChB DRCOG MRCGP
General Practitioner
Leeds, UK

Dr. med. **Gunther Eysenbach**
Head, Research Unit on Cybermedicine, Department of Clinical Social Medicine, University of Heidelberg, Heidelberg, Germany
Assistant Professor, Department of Health Policy, Management and Evaluation, University of Toronto and Senior Scientist, Toronto General Research Institute, University Health Network, Toronto, Canada

Hamish S. F. Fraser MB ChB BSc MRCP MSc
Instructor, Children's Hospital Informatics Program, Harvard Medical School and Research Affiliate, Laboratory for Computer Science, Massachusetts Institute of Technology, Boston MA, USA

Fiona Godlee MB ChB BSc MRCP
Editorial Director (Medicine), BioMed Central
London, UK

Trisha Greenhalgh OBE MD FRCP FRCGP
Professor of Primary Health Care, University College London
London, UK

Beverley Kane MD
Chair, American Medical Informatics Association Task force on Clinical Use of Electronic Mail with Patients
Redwood City CA, USA

Grant Stuart-Black Kelly MB BS
General Practitioner, Chair, British Medical Association Information Technology Committee and Chair, Department of Health Encryption Programme Board, Chichester, UK

John Mack MS MPhil
President, Internet Healthcare Coalition and President, VirSci Corporation
Philadelphia PA, USA

Adrian Midgley MB BS
General Practitioner
Exeter, UK

Jane Rowlands BA DipLib ALA
Sub-Librarian (Database Services), British Medical Association Library
London, UK

Pritpal S. Tamber MB ChB
Assistant Editor (Medicine), BioMed Central
London, UK

Peter D. Toon MSc MRCGP
Senior Lecturer, Open Learning Unit, Department of Primary Care and Population Sciences, University College London
London, UK

Johanna I. Westbrook PhD MHA GradDipAppEpid BAppSc(MRA)
Associate Professor and Deputy Director (Clinical), Centre for Health Informatics, University of New South Wales
Sydney, Australia

Richard Wootton PhD DSc
Professor of Online Health, Centre for Online Health, University of Queensland
Brisbane, Australia

Jeremy C. Wyatt DM(Oxon) FRCP(Lon) F(ACMI)
Director, UCL Knowledge Management Centre and Reader in Medical Informatics and Public Policy, University College London
London, UK

1 Introduction

What is the Internet?

- The Internet is a worldwide network of computer networks (an *inter-net*work) linked by a set of common rules (TCP/IP).
- Neighbouring networks co-operate to share information and allow communication across their networks as if they were one entity.

How do I get Internet access?

- Some computers connect to the Internet via an ordinary telephone line, modem, and a commercial Internet service provider for free or for the cost of a local telephone call.
- Others connect via an academic, institutional, or other network, or via newer media such as digital TV.
- The speed of any connection is in part determined by the information-carrying capacity of the network ('bandwidth').

Why should I bother?

- The Internet can be used to communicate, deliver clinical care, for medical and patient education, for research and current awareness, and for medical publishing and commerce.
- The Internet allows you to harness the power of information technology to meet the increasing expectations of healthcare consumers and demands of professional regulation, at little cost.
- In the UK the National Health Service network (NHSnet) connects every GP surgery and hospital to the Internet.

What is electronic mail?

- Electronic mail (e-mail) involves 'posting' a text message to one or more recipients with a unique e-mail address.
- E-mail can be stored on the network until the recipient clears their 'mailbox'.

continued

- The advantages of e-mail include convenience, speed, low cost, legibility, reproducibility, storability, and the ability to attach computer files.

What is the World Wide Web?

- The Web is the ultimate 'point-and-click' interface to the expanse of inter-linked information on networks spanning the globe.
- Web 'pages' may contain text, pictures, programs, multimedia, and links to further pages or files.
- To locate and view a Web page, simply type its unique address (URL) into your Web browser.
- Web-based information is increasingly machine-readable via technologies like XML and metadata.

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1.1 Introducing the Internet

Bruce McKenzie

Terms such as 'Internet', 'e-mail', and 'World Wide Web' are commonplace in medical journal articles. Few of us can now claim complete ignorance as to their meaning. Many of us, however, would struggle to explain the technologies behind them, or what relevance they have to clinical practice. While most of this book concentrates on the latter, this chapter and the three that follow seek to provide a basic understanding of what the Internet itself is all about and how to access it.

What is the Internet?

In essence, the Internet is simply a worldwide network of computer networks (see Fig. 1). The forerunner of the Internet as we know it was a US military resource-sharing project in the late 1960s called the Advanced Research Projects Agency Network, or ARPANET [1]. Popular rumour suggested that ARPANET might make American military communications invulnerable to nuclear attack by building in 'error tolerance' [2], or the ability to resist disruption. Academic and government networks began utilizing the robust networking standards created through the development of this and other networking concepts during the 1970s and 1980s. Helped by the increasing availability of personal computers in the 1980s, the 'Internet' (as it had come to be known) began to flourish. In 1990 ARPANET was replaced by the faster NSFNET (the US National Science Foundation Network) as the Internet 'backbone' and, after the lifting of restrictions, this opened the door to commercial Internet use. Riding on the growing popularity of the newly invented World Wide Web, by the early 1990s the Internet had become accessible to virtually anyone who owned a computer. It now connects together governments, academics, businesses, non-profit institutions, professionals, and millions of individuals across the planet. It does not connect millions more who have been marginalized by the 'digital divide' (see Chapter 1.4).

When connected to the Internet individuals and organizations have access to all of the resources stored on the many public-access networks

Fig. 1 The Internet is a worldwide computer network created by linking many smaller networks together.

that make up the Internet. These resources include informational text files, software, electronic magazines, journal articles, pictures, sounds, video clips, and animations, etc. The Internet is in many ways like a 'virtual community' on your desktop, including the libraries, shops, and meeting places you would find in the 'real' world. Unlike the real world, distance becomes irrelevant as your computer effectively becomes a window through which you can instantly access services that might be located thousands of kilometres way.

A transport analogy

Perhaps the easiest way to understand the basic anatomy of the Internet is by analogy to a transportation network. To move around a city we might use that city's public road or rail network. There may be some pathways we cannot take—a private road, for example. By linking individual cities together with major public road, rail, or air links, people can travel freely between cities. As we travel we are subject to a set of rules, such as the Highway Code, to ensure we get safely from A to B.

A set of rules

Linking computers together (a computer network) allows information to travel freely from one computer to another. Links can be made using cables or by other types of networking technology (the roads and rails). Access to some parts of the network may be prevented (the private roads). Whole computer networks can be joined together (the major road, rail or air links) to enable us to reach resources or people elsewhere—creating a vast '*inter-net*work'. Each network in the link must understand the same language so that communication is possible. The Internet, with a capital 'I', is the name given to the worldwide network of computer networks that all understand a language called 'TCP/IP'—a kind of computer Esperanto (and our 'set of rules'). TCP/IP is an abbreviation for the 'Transmission Control Protocol/Internet Protocol' communications protocols. Some networks don't use these protocols, or choose not to link up with other networks, and so may not be a part of the Internet (see Box 1).

Mutual co-operation

It is, however, another kind of protocol that really makes the Internet possible—mutual co-operation. Through taxation we pay for the maintenance

Box 1 Is every computer network part of the Internet?

Some computer networks are not connected to the Internet at all, often because they contain private information. Strictly speaking, only networks that use TCP/IP to communicate with other networks are part of the Internet proper. Networks that use alternative communications protocols or 'rules' may be linked to the Internet via a 'gateway' that translates between different network protocols. Being a part of the Internet has informally come to mean that you have some sort of ability to communicate electronically with other Internet-connected people.

of the road network in our own country. If we drive to another country we generally don't pay extra to use their road networks. Instead, these countries co-operate to allow traffic to pass without charge via their own road networks.

In the case of the Internet, each network that forms a part of the whole is maintained and paid for by the people or organization responsible for it. By co-operating with neighbouring networks, it is possible to send information from one network to another via intermediate networks. This explains why you can connect to a transatlantic computer on the Internet for no more than the cost of a local telephone call—you pay only for connecting to the part of the network that gives you access. Co-operation on this scale does, however, require some kind of consensus (see Box 2). The similarities between transportation networks and the Internet are summarized in Table 1.

Box 2 Consensus on the Internet

The Internet is 'controlled' by everyone and by no one. Although ownership of the physical infrastructure is largely commercial, the Internet Society (ISOC) is a non-commercial, non-governmental umbrella organization for several bodies concerned with developing and defining Internet standards by consensus, and for addressing other issues relating to the use of the Internet. For more details see:

http://www.isoc.org/

These bodies include the Internet Engineering Task Force (IETF), concerned with the evolution of the Internet architecture, and the Internet Corporation for Assigned Names and Numbers (ICANN), responsible for the domain name system (see text). The World Wide Web Consortium (W3C) oversees the development of the World Wide Web (see Chapter 1.4).

What services does the Internet provide?

Three types of service were originally available on the Internet for sending and receiving information:

- Electronic mail (e-mail) allows us to send messages from one computer to another either as a personal message, or to a group of people via a mailing list or newsgroup (see Chapter 1.3).
- File Transfer Protocol (FTP) allows us to upload or download files.
- Telnet lets us log in to another computer remotely (i.e. from elsewhere) and use it by typing commands as if we were at the keyboard attached to that computer.

Table 1 Using a transportation system to understand concepts in computer networking

Parallel	Transportation network	Computer network
Small link	A city's road and rail network	A small computer network (known as a 'local area network', or LAN)
Private link	A private road (perhaps protected by a locked gate)	A restricted access nework link (perhaps protected by a 'firewall'—see p. 132)
Major link	A major road, rail, or air link	A link between networks ('inter-networking') using cables, satellites, etc. (known as a 'wide area network', or WAN)
A set of rules	The Highway Code and other regulations	Transmission Control Protocol/Internet Protocol ('TCP/IP' for short)
Mutual co-operation	Driving across national borders	Access to global networked resources

These 'traditional' services appeared early in the history of the Internet but remain crucial to the workings of more recent services. Later generation services have greatly shaped the way people use the Internet. The World Wide Web (WWW or Web) is by far the most important of these newer services, giving the Internet a friendly 'point-and-click' front-end (see Chapter 1.4). Other Internet services are summarized in Box 3. Both traditional and later generation services are referred to collectively as 'Internet services'.

Clients and servers

Internet services typically rely on a client–server model. A client is a program on the user's computer that provides an interface for sending instructions to, and receiving information from, a server. A server is program running on a machine elsewhere on the Internet that fulfils requests made by the client (such as accessing a database). For example, the client you use to send and receive e-mail is your e-mail program; the client you use to view the Web is your Web browser. In fact Web browsers often act as clients for several types of server (e.g. Web, mail, and FTP servers). A single client can simultaneously access several servers, while a server can simultaneously entertain many clients.

Box 3 Other Internet services

Information retrieval tools share the characteristic of helping to locate information and/or files held on various Internet computers. In addition to the Web, these tools include Archie, Gopher, and Wide Area Information Servers—each unique in its capabilities to retrieve usable information:

- Archie: a searchable database of the location of named files available for download.
- Gophers: organize information on different computers into a menu and, with the help of the 'Veronica' search program, can lead you to relevant resources.
- Wide Area Information Servers (WAIS): go further than Archie and can search within the contents of files looking for a match to your query.

Other Internet services are primarily concerned with communication and entertainment:

- Internet Relay Chat (IRC): people converse with others in 'real-time typing'.
- Multi-user Dungeons or Dimensions (MUDs): used for text-based role-playing games.
- MOOs (MUDs, Object-Oriented): use 'objects' (including characters) in virtual rooms to support real-time conferencing and interaction.
- Streaming audio and video: audio or video is received 'on-demand' as a broadcast, commencing playback before the download is complete.
- Internet telephony: with appropriate equipment the Internet can be used like a telephone ('voice over IP') or videophone, avoiding long-distance charges.

Navigating the Internet

To use any of the Internet services, you need a basic understanding of how computers and the resources on them are uniquely identified. The three basic ingredients for Internet navigation are: IP addresses, domain names, and uniform resource locators.

Internet Protocol addresses

An Internet Protocol or IP address uniquely identifies every machine directly connected to the Internet. This address takes the form of a grouping of four numbers separated by full stops, such as 158.152.64.237. The Internet uses this numerical address to ensure e-mails and Web pages get to your computer by tagging data 'packets' with it (see Box 4).

The Domain Name System

IP addresses aren't exactly memorable, and can in fact change occasionally. To overcome this the Domain Name System (DNS) uses a hierarchy of named 'domains' or subdivisions to make things more intuitive. The broadest

Box 4 All about packets

To a computer an e-mail or Web page is just 'data'—strings of zeros and ones (binary code) that only computers understand. When you connect to the Internet your computer is given a unique IP address, like an ID tag. Data that is intended for your computer is broken up according to TCP/IP rules into segments called 'packets', each tagged with 'from', 'to' (i.e. your ID), and error-correction information as well as unpacking instructions. A similar thing happens when you send data to another computer, as when you request a specific Web page. During transit these packets are handed from network to network in pass-the-parcel fashion, getting ever closer to the destination IP address. The packets may thus arrive by any number of routes dependent upon which routes are open, although the shortest route is preferred. It's quite a bit more complicated than this in reality, but the principles hold!

category is called the 'top domain', generally indicating the type of institution or a country. A variable number of sub-domains might describe the name of an institution, a particular department, a person, or a certain machine. The combination of these elements is called a 'domain name'. Dedicated computers called 'DNS name servers' invisibly map domain names to the correct IP address. Some example domains are given in Box 5.

Box 5 What domain names tell us

.edu	A domain belonging to an American educational institution.
.com	A domain belonging to an American commercial institution.
.ac.uk	A domain belonging to a UK educational (academic) institution.
.co.uk	A domain belonging to a UK commercial institution.
.pro	A domain belonging to a professional, such as a doctor.
.nhs.uk	A domain belonging to the UK National Health Service.
.doh.gov.uk	A domain belonging to the UK government, Department of Health.

For information about domain names see:

http://www.icann.org/

Uniform resource locators

When people refer to 'Internet addresses', they are talking about URLs. Uniform resource locators (URLs) use a standardized syntax to describe the location and method of accessing Internet resources [3]. URLs (a type of URI—p. 34) are used extensively to navigate the Web. By typing a URL into a Web browser, you can find any specified resource without having to search for it manually, directory by directory. The basic format of URLs is explained in Box 6.

Box 6 Internet addresses (URLs) explained

The basic format of URLs you will see on the Web is service://host[:port]/path

The service element identifies the type of Internet service. For example, 'http' refers to the HyperText Transfer Protocol (see p. 34) used by the World Wide Web. The host element is the domain name (see text) of the actual server hosting the service. The optional port element specifies a 'contact address' for the server application on the host (a number, such as '80'). The path element is used to specify the directory location or 'path name' and/or file name of a particular resource on that host. The '/' symbol is used to separate out the different elements in the path name. For example:

http://www.doctor.net:80/pages/medic.html

This example tells our Web browser to look for a Web (http) server on a computer with the 'www.doctor.net' domain name, using port 80, for a file called 'medic.html' in the 'pages' sub-directory.

Tip: URLs must be spelled exactly. If a URL doesn't work, check the spelling. If a file name has changed, you still may be able to find the file by dropping the file name and ending the URL with the '/' symbol.

The evolving Internet

Two American research projects founded in 1996, the Next Generation Internet (NGI) and Internet2 initiatives, are exploring technologies that may eventually help to evolve the Internet we know today. The US government-sponsored NGI is testing higher-speed electronic networks and new applications to make use of them [4]. The Internet2 project is a non-profit consortium of universities and corporations also exploring new applications for high-speed networks [5]. Healthcare institutions are among the project members and some of these applications are of a medical nature, such as telemedicine (see Chapter 3.3). In addition to boosting speed, these initiatives are concerned with prioritizing traffic (e.g. delivering real-time video data before e-mail), improving network reliability, and ensuring confidentiality—all issues critical to medical telecommunications. Other non-technological issues—such as censorship, privacy (data collected on Internet users) and the protection of intellectual property—will need to be resolved by society as a whole.

References and notes

1. More background information about the Internet, including its history, can be found via the Internet Society (ISOC) Web site at http://www.isoc.org/
2. 'Error tolerance' implies that, in the face of localized failures, the network as a whole will remain operational. This does not mean that the Internet is totally safe from malicious attack. See Albert R, Jeong H, Barabasi AL. Error and attack tolerance of complex networks. *Nature* 2000 Jul 27; 406(6794): 378–82.
3. See RFC 1738. RFC or 'Request for comments' documents are a record of evolving Internet protocols and standards. Available from http://www.ietf.org/rfc.html
4. The Next Generation Internet home page is at http://www.ngi.gov/
5. The Internet2 home page is at http://www.internet2.edu/

1.2 Access to the Internet

Bruce McKenzie

Types of Internet access

To use the Internet, you must have access to one of the networks forming a part of it. In the UK health sector this could mean access via an 'intranet' (see Box 1), an institutional network like JANET (see Box 2) or NHSnet (see Box 3), or via one of the many companies offering Internet access to the public (ISPs: see below). Whatever their method of Internet access the biggest issue for many users is the speed or 'bandwidth' of the connection (see Box 4).

New methods of accessing the Internet have emerged as a result of convergence between Internet and other technologies. High-bandwidth

Box 1 What is an intranet?

An intranet is a private computer network set up to share resources and exchange messages based on Internet technologies (TCP/IP protocols, Web browsers, etc.). It may be linked to the Internet itself via a secure 'gateway' (or firewall—see p. 132) that typically protects sensitive internal information from outside access.

Box 2 What is JANET?

The Joint Academic NETwork (JANET) was created in 1984 to interconnect the UK academic and research community. Although JANET originally relied on an alternative networking protocol (X.25), it began using TCP/IP in 1991. This gave medical students and academics full Internet access using the same client software as is provided to dial-up users (see text). Several 'SuperJANET' projects have since concentrated on improving network capacity, or bandwidth (see Box 4). For information on obtaining Internet access via JANET, contact the Computing Service at your university or institution. The JANET home page is at:

http://www.ja.net/

Box 3 What is NHSnet?

NHSnet is a dedicated wide-area network (WAN) linking UK National Health Service (NHS) bodies and providing services such as internal messaging (interpersonal e-mail and computer-to-computer electronic data interchange, or EDI) and non-public Web pages known as NHSweb. It is anticipated that NHSnet, which went 'live' in October 1995, will be used for applications such as electronic health records, results reporting, online prescribing and appointment booking, electronic referrals and discharge letters, and telemedicine (see Chapter 3.3). A security-minded connection agreement and encryption programme (p. 132) help ensure the confidentiality of patient-identifiable information on the network.

NHSnet uses the same TCP/IP protocols (p. 11) as the Internet. A secure Internet gateway provides external e-mail and Web access to NHSnet users. The URL (p. 11) of a Web site within NHSweb is prefixed with 'nww' in contrast to the typical 'www' prefix of Internet-based sites. NHSnet will replace its original e-mail (X.400) and EDI (EDIFACT) standards in favour of 'Internet standard' SMTP (p. 26) and XML (p. 43).

Connections to NHSnet from general practice (GP) were initially inhibited by concerns about network security, reliability, performance, and costs [1–3]. For details of the program to connect GPs to NHSnet see the Project Connect Web site at:

http://www.gpnet.nhsia.nhs.uk/

Box 4 The bandwidth issue

Covering a certain number of miles on a major road like the M1 ordinarily takes less time and allows more people to travel at the same time than, say, travelling the same distance on a smaller B road. On the Internet some information pathways can likewise be considered as being wider than others, carrying more 'traffic' at greater speed. This information-carrying capacity is called bandwidth—a measure of how much data can be transmitted through an information pipe at different frequencies within a certain time. Bandwidth is strictly measured in hertz, but this is commonly equated to kilobits per second (Kbps, sometimes abbreviated to just 'K') or megabits per second (Mbps). Bits are the individual zeros and ones that computers use to store data (i.e. binary code). For example, a '56K' modem is *theoretically* capable of connecting to the Internet at 56 Kbps (56 000 bps).

Using a high-bandwidth ('broadband') pipe to connect to the Internet does not *guarantee* a high-speed connection. As on the M1, parts of the Internet can experience rate-limiting traffic jams. Sometimes more traffic can get from A to B on a smaller road than many drivers on a larger one, since the space on the road must be shared equally. Bandwidth is similarly shared on the Internet.

Tip: Using the Web at 'quiet' times (e.g. early morning UK time) avoids the 'World Wide Wait' resulting from network congestion.

(broadband) connections are increasingly available, typically offering connection speeds faster than 500 Kbps [4]. These connections are usually 'always-on' so there is no need to dial in every time you want to use the Internet (although a firewall to protect your computer is advisable: see p. 132). Broadband connections are more likely where a number of users need to share the same Internet connection. The cost of such connections is variable and likely to lessen as they become more widespread.

Until then those of us without broadband or network-based Internet access at work will probably continue accessing the Internet at home via personal computers and dial-up low-bandwidth ('narrowband') links using a telephone line and modem. Consequently the requirements for this type of access are the focus of this chapter. Other 'mass market' technologies presently used to make Internet connections in the UK are summarized in Box 5.

Box 5 Internet access technologies in the UK

ISDN

Integrated Services Digital Network (ISDN) connections operate like dial-up modem connections, but use a dedicated digital telephone line and hardware called a terminal adapter. Data can be transmitted at 64 to 128 Kbps (over twice as fast as a 56K modem), depending on whether you are sending it down one or two channels. These rates are achieved by transmitting a stream of digital bits, rather than performing the modulation/demodulation used by modems over ordinary telephone lines. To use ISDN for Internet access your service provider must offer an ISDN line to connect to.

Cable

Internet access can be obtained using the same network that provides digital television via fibre-optic cable to the end of your street, leaving the telephone free. This always-on connection occupies a cable channel that is not used to deliver TV broadcasts. Cable has a very high bandwidth but because this bandwidth must be shared among cable users, it is common practice to limit data rates available to individuals (e.g. to 512 Kbps for downloads, 128 Kbps for uploads). These rates are unlikely to be achieved if many users are online in your area. A 'splitter' separates the data channel from the TV channels and sends it via a 'cable modem' that plugs into your computer.

continued

Box 5 continued

ADSL

The telephone service uses only a small frequency range over the potential bandwidth of ordinary telephone lines. Using upgraded equipment at your local telephone exchange, digital subscriber line (DSL) connections access much of the remaining bandwidth (if you live within several kilometres of the exchange—the signal degrades over longer distances). These connections are always on and in the UK allow download rates of 512 Kbps to 2 Mbps, and upload rates of 256 Kbps. The difference in download/upload rates is why this flavour of DSL is called 'asynchronous', or ADSL. A signal splitter at either end of the connection allows for simultaneous data and voice/fax communications. An ADSL modem links the data signal to your computer. See the DSL Forum at http://www.adsl.com/

Mobile

A personal digital assistant (PDA, or hand-held) or laptop computer may be connected to a data-capable mobile phone for wireless Internet access, allowing you to manage your e-mail or surf the Web on the move. The main limitation of mobile access is the current low bandwidth of the GSM (Global System for Mobile Communications) radio networks used (9.6 Kbps, but developments such as the General Packet Radio Service are set to change this). An interim alternative mobile solution is WAP (Wireless Application Protocol). WAP-capable mobile phones use a built-in mini-browser to access a limited selection of Web pages in a special format and to manage e-mail. See GSM World at http://www.gsmworld.com/ and the WAP Forum at http://www.wapforum.org/

Digital TV

Digital TV services (cable, terrestrial, or satellite) now offer Internet access. This may vary from basic e-mail only, through special-format content, to 'full' Web access. These services typically use a set-top box (STB) with a built-in modem requiring a telephone connection, or a cable connection. Your TV functions as the screen and an over-sized remote control may provide a keyboard. It may be possible to attach a printer. Limitations include the inability to download and store files or to view sophisticated Web pages. A stand-alone or integrated STB is also available for use with analogue terrestrial TV.

Dial-up access

Dial-up Internet access typically requires a personal computer loaded with appropriate software, a modem, an ordinary telephone line, and an Internet service provider.

A computer

Almost any computer running a current operating system (e.g. Microsoft Windows, Mac OS, Linux, etc.) should be adequate. Current prices for 'best buys' and typical configurations are often listed in computer magazines. Newer versions of programs for using the Internet—especially for browsing the Web—place ever-increasing demands on your computer hardware (particularly on the processor speed and memory). It is therefore not unreasonable to suggest that you buy the best system you feel you can afford.

Appropriate software

All the software needed to connect to the Internet will normally be preloaded on new computers, or provided free as part of an access package (see below). This software includes the 'behind-the-scenes' networking components of the operating system (such as TCP and PPP: see Box 6) and various client programs (at least an e-mail client and Web browser). Software to screen for computer viruses is a recommended addition (see p. 134).

Box 6 What is PPP?

Computers that connect to the Internet via telephone lines need a kind of interpreter to make TCP/IP (p. 7) understood over this type of intermittent connection. Point-to-Point Protocol (PPP) fulfils this role by modifying IP packets (see Box 4 on p. 11) to allow them to be sent over telephone lines. It therefore acts as a network interface so that client software on your computer can interact directly with server software on the Internet, typically via the familiar 'user friendly' interface of your operating system. PPP software typically serves as your 'Internet dialler' for connecting and disconnecting. Serial Line Internet Protocol (SLIP) is a much less common alternative.

A modem

Although the telephone system is ideal for carrying human voices, computers only understand digital information. To transmit information from one computer to another over a telephone line it is therefore necessary to change (or modulate) the digital information into sound and—at the receiving computer—change it back into digital form (which is called demodulation). A modem is a device (often inside new computers) that performs *mod*ulation–*dem*odulation, converting computer language to sound and back over telephone lines (see Fig. 1).

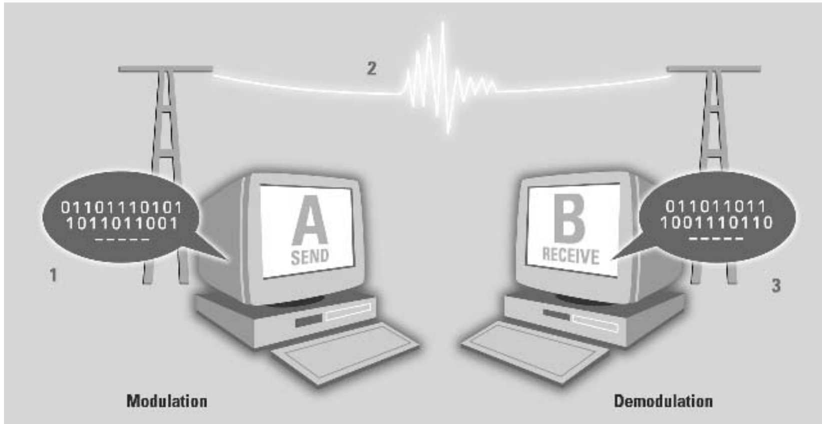

Fig. 1 How modems work. Digital information on the sending computer (1) is converted to sound for transmission over telephone wires (2), then back to digital information on the receiving computer (3).

Modems are governed by various protocols, the most important of which relate to speed. Top of the line 56K (or V.90) modems are theoretically capable of downloading/receiving at speeds of up to 56 Kbps and uploading/sending at up to 33 Kbps, although actual speed depends on several variables (such as 'line noise'). In addition to speed protocols, modems:

- use data-compression protocols to speed up data transfers
- use error-correction protocols to make sure data are received intact
- use 'handshaking' to negotiate on common protocols to employ (often audible).

A telephone line

A modem connects to your phone jack just as a telephone or answering machine does. If you have a single telephone line then using your modem prevents you from simultaneously making or receiving voice telephone calls. Some people install a second line to overcome this.

An Internet service provider

An Internet service provider (ISP) is an organization providing the resources necessary to make your computer a part of the Internet. ISPs provide dial-up users with Points of Presence (PoPs), banks of modems that allow access to the ISP's own high-speed Internet link. Internet and computing magazines often include listings on the performance of ISPs, the services they offer, and associated costs. ISPs offering access to doctors only may be advertised in the medical press. Using a combination of ISPs can get the best access for certain times or tasks [4]. There are a number of general considerations that may help you choose an ISP:

- Service provision: Virtually all ISPs now offer the full range of Internet services. Some also offer 'value-added' services such as proprietary Web content. Many offer a range of account options to suit different requirements.
- Call charges: An ISP's services are typically available nationally at local call telephone rates. If you often change address (as many junior doctors do) this avoids your having to change ISPs when you move. Unless you are a 'light' user, even at pay-as-you-go local call rates costs can soon mount up. To overcome this some ISPs offer unlimited time on the Internet for a fixed subscription, either at off-peak times (evenings and weekends) or around the clock (so-called '24/7' access). Such services are often popular with 'heavy' users so may be over-subscribed.
- Speed of access: An ISP should support 56K modem connections, the current standard. Individual ISPs also differ in the capacity at which their own network operates, and in the speed at which they connect to the rest of the Internet; this ultimately influences the speed at which dial-up users can access remote resources.
- Set-up costs: There may be an initial set-up fee to cover the creation of your account and/or supplied software.
- Support facilities: Be sure the ISP supports your type of computer (if you have a Mac, for example). New users will want to check that telephone support is available at times when they will be using the service (and the rate calls to it are charged at). Online 'new user' forums, FAQs (frequently-asked questions), or e-mail contacts are little help if you can't *get* online! It is unusual for ISPs to supply printed instructions or a manual.
- Internet client software: Most ISPs will supply a CD-ROM including client software (e.g. for e-mail, Web browsing, etc.). This may be pre-configured, or you may be given 'do it yourself' instructions that will usually specify settings for TCP/IP (including your IP address if you are given one); settings for PPP (including your account/user/login name, password, and modem access number); mail server addresses (for sending and receiving e-mail—see p. 26); and a news server address (for access to newsgroups). You may need to select your personal e-mail address(es) and Web home (start) page. Not all ISPs let you choose your own client software—a problem only if you wish to use a certain client.

- Choice of e-mail address or domain name: Do you have the option to specify at least the first part of your e-mail address, or will it be decided for you? How many e-mail addresses can you have? Some providers also let you choose a unique domain name (p. 10).
- Personal Web space: Many ISPs offer 'free' Web space to individual customers, so you can create and publish your own Web site.

Why access the Internet?

Having considered the 'what?' and 'how?' of connecting, why should you access the Internet? A number of reasons may apply:

Political reasons

The UK Government aims to:

- Achieve universal access to Internet services for all those who want it by 2005 [5];
- Adopt common Internet standards (e.g. XML—p. 43) for use by all public-sector information systems, including the health service (NHS), with a Web browser interface [6];
- Connect every general practice and hospital to NHSnet, permitting Internet access [7].

Medical reasons

- The Internet can be used to communicate, deliver clinical care, for medical and patient education, for research and current awareness, and for medical publishing and commerce.
- Electronic communications and resource sharing could help deliver cost-effective and integrated healthcare.
- Harness information technology to meet the increasing expectations of newly empowered patients and demands of professional regulation—at little cost.
- The Internet is a tool—like the stethoscope or coat-pocket handbook. It extends our life experience and complements our ability to learn and practice medicine.

General reasons

- Around-the-clock availability from home or work.
- It's more interactive than TV (look at what you want, not what you're shown).

- Keep in touch with friends, family, others.
- Downloadable computer software and online support.
- Current information about anything and everything.
- Convenient online shopping (books, music, etc.).
- Self-publishing with minimal investment.
- An easy-to-use 'point and click' Web interface.
- Enjoyment (it doesn't have to be all work and no play!).

The decision to connect is not, however, one-sided. Resources come and go. People come and go. Debate rages over commercialization and 'appropriate use', freedom of speech, 'crackers' (people who attempt to gain access to other people's computers), and protection of sensitive data. This is because the Internet is more about people co-operating, less about technology.

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1.3 Introducing e-mail

Bruce McKenzie

Electronic mail (e-mail) is one of the most versatile services on the Internet. It can be used to conduct personal conversations, for sending or receiving computer files, for automated information retrieval, for group discussions via mailing lists or newsgroups, or even to send or receive faxes. This chapter provides a very brief introduction to the use of e-mail.

Personal e-mail

Just as a letter written on paper can be delivered to a unique postal address, a message typed on a computer can be delivered to a unique electronic address. Personal e-mail addresses typically take the form 'person@computer.name', where the first part is the name of the account holder and the second part (after the '@' symbol) is the domain name (p. 10) of that person's computer.

E-mail is probably unrivalled in terms of convenience and cost-effectiveness. There is no need for stationery, stamps, or postmen. E-mail can be sent to another time zone without waking the recipient—and their computer does not need to be on at the time the message is sent. Compared to most handwriting it is highly readable, and can easily be edited and incorporated into other documents such as word-processor files. Current e-mail programs make it very easy to attach non-text files (e.g. illustrations) to an e-mail message, avoiding the sometimes messy exchange of floppy disks. Because electronic data is so reproducible, it is a simple matter to copy parts of a message into a reply, or forward a message to other recipients. Furthermore, it is the service least demanding on your computer or method of Internet access.

Exactly how long a message takes to get from person A to person B depends on several factors including how much traffic is on the Internet, how many networks are involved in handling the message, and how often person B checks their mailbox. If your message can't be delivered, the system will normally send a 'failed delivery' notice to the author of the message (hopefully with a clue as to why).

E-mail software

To use e-mail, you will need access to a computer capable of exchanging mail with the Internet, an account on that computer, and appropriate client software (p. 9). Client software is often pre-loaded on new computers, and is readily obtainable on computing magazine cover disks or from Internet service providers. You will often have to configure the software for use with the e-mail account supplied by your Internet service provider (Box 1). Most clients have a standard set of features, such as the ability to manage several accounts, directly reply to received messages, mail forwarding, and the ability to send multiple copies to other individuals. There should be an option to attach a file stored on disk to your message; a good client will automatically encode the file (see below) and likewise decode it at the receiving end. An address book allows you to enter a person's name and e-mail address once, and subsequently address messages to them simply by choosing their name from a menu or by typing the first few letters of a shortened 'nickname'. Some e-mail clients also manage network news (see below). E-mail can also be managed on the Web without using a dedicated client. Although Web-based accounts (e.g. MSN Hotmail, Yahoo! Mail) tend to offer only basic e-mail management, Web mail can be accessed from any computer set up for Web access. If you are not already well versed in using e-mail clients, consider obtaining training or purchasing one of the many general Internet guidebooks that are available.

Box 1 Configuring e-mail software

When configuring their e-mail account most Internet users will have come across an address for an SMTP server used for sending e-mail, and a POP3 server used for receiving it. SMTP (Simple Mail Transport Protocol) and Post Office Protocol version 3 (POP3) are Internet standards [1, 2]. A less well-known alternative protocol for receiving e-mail—Internet Message Access Protocol version 4rev1 (IMAP4)—is proposed as an Internet standard [3]. Your Internet service provider should tell you which type of account you have, and what server addresses to use.

Ensuring privacy

E-mail is not secure by default. Anybody (with appropriate privileges) on any machine through which your e-mail passes will be able to read it. There have been (very infrequent) reports of e-mail being routed to the wrong address. Bear this in mind if sending confidential clinical details: potentially sensitive e-mail should always be encrypted (converted into an unbreakable code). See Chapter 3.4.

Using attachments

There are two basic types of computer files: text files and binary (program) files. Without going into detail, the importance of the difference is that e-mail can normally contain text only. It is possible, however, to convert binary files (like Microsoft Word documents) into text via a process known as 'encoding'. Encoded files can be transferred as text-only e-mail from one computer to another where they can be decoded back into usable program files. The prevalent Internet protocol for encoding binary files into text is called MIME. MIME, an acronym for Multipurpose Internet Mail Extensions [4], identifies the type of file(s) buried within each part of an encoded message using 'MIME types'. Web browsers (p. 34) also make use of MIME types. Adding and saving attachments using MIME, with the necessary encoding and decoding, is performed transparently by modern e-mail clients (Fig. 1). Attachments can harbour computer viruses—so make sure you take appropriate precautions (see Chapter 3.4).

Information retrieval

Many Internet services (p. 8) can be utilized via ordinary e-mail messages. Although not as straight forward as using dedicated client software, this means most of the Internet (including files in FTP archives and Web pages) is retrievable by those with an e-mail account only (as may be the case in the developing world). To learn more about accessing the Internet by e-mail, send 'get lis-iis\e-access-inet.txt' in the body of a message to 'listserv@jiscmail.ac.uk'.

Fax

Several services, both free and commercial, offer a facility to convert e-mail into fax format. In this way faxes can be sent without international call rates to those who have a fax machine but not a connection to the Internet. For more information, see:

http://www.savetz.com/fax/

Mailing lists

E-mail can be used for more than interpersonal (one-to-one) communications; it can also facilitate one-to-many exchanges. To send or receive public messages, you could subscribe to a special-interest mailing list.

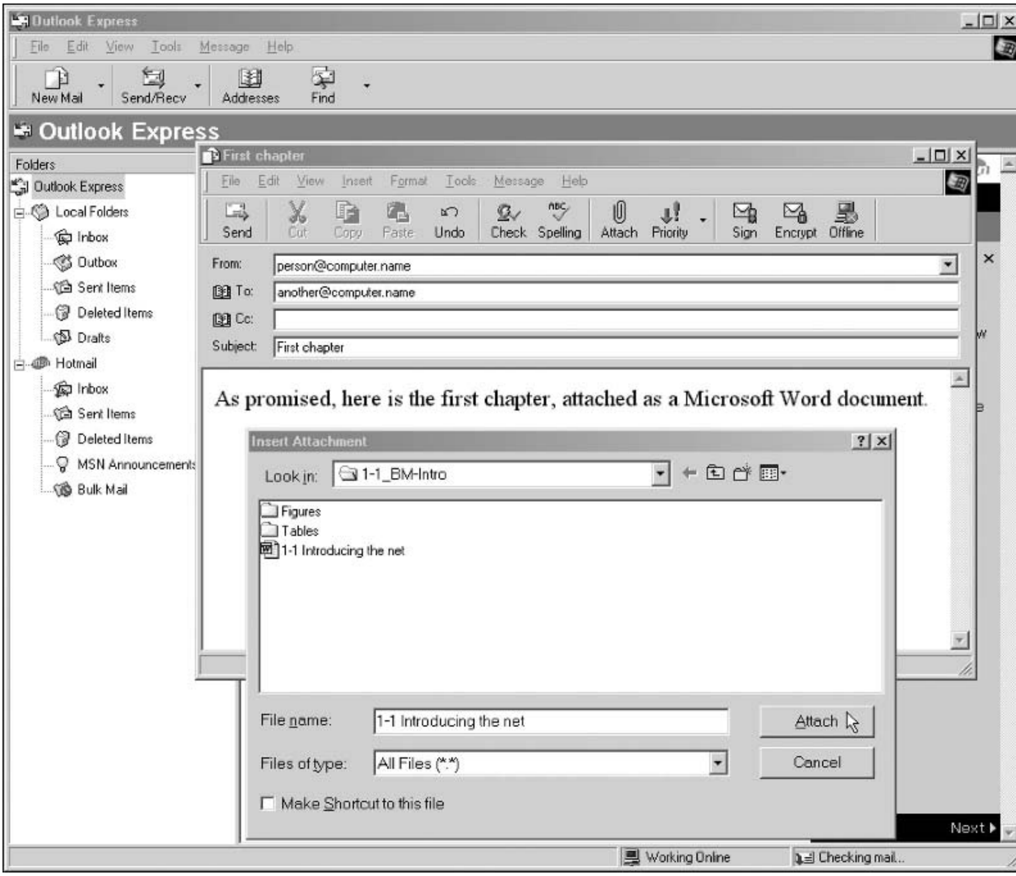

Fig. 1 Modern e-mail clients make it easy to send documents over the Internet without the user needing to be aware of the behind-the-scenes encoding technology.

Unlike print magazines, articles on most mailing lists are sent out to all subscribers as they are written. However, some mailing lists do produce digests; they batch a number of articles into a single file and mail it to subscribers at a certain interval. Typically these lists are moderated; the list owner will review each message sent to the list and authorize its distribution to all subscribers. This can improve the quality of the mailings for individual subscribers who do not wish to read erroneous messages sent to the list, or those that wander off the topic. Not all mailing lists are public either. Although most do allow anybody to subscribe via an automated process, others require the prospective subscriber to contact the list owner and request a subscription personally. Rarely this may require proof of professional status, such as a professional registration number.

Subscribing to a mailing list, therefore, essentially means that you have added your name to a list of e-mail addresses which is accessible to a program (or person) operating the list. In many cases mailing lists require little human intervention once they have been established. The programs that manage mailing lists are known collectively as 'list servers'. Instead of users sending multiple copies of messages to every other subscriber, a single message is sent to a specific computer running a list server. The list server either passes the message on to the moderator for approval, or automatically redistributes the message to other subscribers. Some electronic journals use list servers for their distribution as well, and so can share the same characteristics as ordinary 'discussion-type' mailing lists.

Using a mailing list can be tricky. This is because of the different conventions used by the various list-server programs on the Internet and other networks. In general, however, using a mailing list involves sending messages to one of three different addresses:

- List-server address: To add your name to the list of subscribers (or manage your subscription), you send a precise command via an e-mail message to an automated list server. The list-server address may be used by many different mailing lists.
- List address: To send a message that will be distributed to all subscribers (perhaps via a moderator), you send a message to the list address, which is unique to each mailing list.
- List owner: To contact a flesh-and-blood list owner (e.g. in the event of difficulty), you send a message to the list owner's personal e-mail address.

Invariably mistakes are made, but sending an incorrect message to the list server will sometimes result in the return of a file telling you of the idiosyncrasies of that particular system. On the other hand, commands sent to the list such as 'unsubscribe'—which should be sent to the mail server—tend to annoy people. Sending the message 'help' to any list-server address (not to the list itself) is a good place to start in your dealings with list servers.

Newsgroups

Network news is a kind of global bulletin board where public messages are organized into subject-specific newsgroups, and passed around the Internet and other networks. The Internet is part of the distribution system for the Usenet newsgroup network (although Usenet as a whole doesn't rely on Internet protocols). Usenet and other newsgroups provide a forum for Internet users to exchange points of view, ask for and give help, etc. Generally, the term newsgroup is something of a misnomer; most groups do not bear 'news' in the usual sense of the word. Newsgroups are organized in a hierarchical fashion, with the name of each group constructed in a way that reveals this hierarchy (see Box 2).

Box 2 The hierarchical nature of newsgroups

Newsgroups are organized into the following main categories, where each 'top-level' heading has a number of subtopics ('*' is a wild card indicating various subgroups):

alt.*	'Alternative', including support newsgroups
comp.*	Computer-related discussions
misc.*	Miscellaneous topics
news.*	Newsgroup administration
rec.*	Recreation
sci.*	Sciences (including the medical sciences)
└──── sci.med	
└── sci.med.aids	
└── sci.med.radiology	
└── etc.	
soc.*	Social and cultural issues
talk.*	Controversy and debate

Network News Transport Protocol (NNTP) is used by machines on the Internet to exchange news over TCP/IP links [5]. As new messages (sometimes called articles) are created at one news site, they are passed on to other news sites (if these sites choose to carry that particular newsgroup). In this way, posting a message to an international newsgroup like sci.med (see below) will see it propagated around the world by a chain of network news servers.

News readers

To browse newsgroups you require a news feed (i.e. a source of newsgroup articles), usually identified by the domain name of your Internet service provider's NNTP news server. This information allows a NNTP news reader client on your machine to connect to the news server and download a list of current articles in the newsgroups to which you have 'subscribed'. Rather than download all the articles, the user only needs to click on the subject line of the particular articles that look interesting. For the most part, news readers behave like e-mail clients, allowing you to create new messages, post replies, save articles to disk, etc. News readers make it easy to follow threads (i.e. to read the next or previous message relating to a particular topic, rather than follow a chronological sequence of unrelated postings). Some popular clients, like Microsoft Outlook Express, function as both e-mail clients and news readers.

The newsgroup sci.med deals with general medical topics, containing questions and answers about the attitudes of healthcare professionals, new therapies, requests for information and diagnoses, etc. Traditionally the sci.med newsgroups played an important role in providing peer support (see Chapter 5.1) but they have been somewhat superseded by the Web. These groups remain open to the public and professional contributions are encouraged. Doctors who post to newsgroups, however, should be aware that doing so can have negative consequences (see Box 3).

Box 3 Consequences of posting to newsgroups

Unfortunately many newsgroups in the sci.med hierarchy have become overrun by obscenity and other irrelevancies. Posts may be rewarded by 'flames'—inflammatory criticisms that may provoke 'flame wars' when other users flame those doing the criticizing. This discourages medical involvement, leaving questions unanswered and advice withheld. Although such experiences are not common, there is reluctance on the part of some doctors to identify themselves online, choosing instead to make anonymous replies to medical questions. As with ordinary e-mail, misinterpretation may result from the absence of non-verbal cues (see Chapter 2.3). Posting also risks being subjected to 'spam'—unsolicited (junk) e-mail, sent by spamers who obtain your e-mail address by trawling through newsgroup postings.

Frequently asked questions files (FAQs) were originally lists of commonly asked questions appearing in various newsgroups, together with their answers (the idea has since been widely adopted on Web sites). Almost any periodically posted informational file is dubbed an FAQ, whether it was written as a response to real questions or not. Many of the FAQs found in the support newsgroups represent an accumulation of a given person's (or newsgroup readership's) knowledge of a particular subject. FAQs serve several purposes. New users are encouraged to read a newsgroup's FAQ(s) before posting a question. In this way others do not have to read and reply to the same questions, but the discussion in the group can move on to cover new ground. Further, they often contain pointers to other documents available on the Internet, and so help new users find their way about.

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1.4 Introducing the Web

Bruce McKenzie

Introduction

For many people, the World Wide Web (WWW or 'Web') and the Internet are virtually synonymous; it could be argued that the Web isn't really in need of introduction. In any case, it is impossible to do the Web justice within a single chapter. Bearing this in mind, the present chapter selectively aims to briefly explore the concepts and history behind the Web and the role of Web browsers. We then look at two issues of relevance to medical use of the Web not discussed elsewhere within this book, before taking time to consider the Web of the future. If this sounds like an introduction followed by a conclusion I offer no apology: middle-ground texts on 'how to use your browser' are readily available.

What is the Web?

The Web is a facility on the Internet that uses the metaphor of a page to present information. Like a book, each page can contain text and pictures, but the Web differs from a book in two important ways. Firstly, whereas the pages of a book are joined via the spine in a fixed order, Web pages are linked together by something called hypertext. In hypertext, you click on a link with your mouse to jump to related information elsewhere on that page, or on another page. The reader is thus free to explore the Web pages in any order that makes sense to him or her. Secondly, Web pages can also contain links to non-text files like sounds, animations, video, computer files, and even small interactive programs. For this reason the term 'hypermedia' is sometimes used to collectively describe the kinds of links within and between Web pages. A simple analogy to help understand the anatomy of a Web site is given in Box 1.

Box 1 Understanding the anatomy of a Web site

Imagine you have dropped a pile of papers on the floor. At the top of the pile is the 'home page'—the place we would ordinarily start from to get deeper into the pile. This page is in contact with (or 'linked' to) several pages beneath it, and each of those pages in turn to several pages beneath them, and so on. We could eventually get to the bottom of the pile following any number of different pathways linking the pages as we move 'forward', or deeper into the pile. Similarly, once at the bottom of the pile we could work our way 'back' toward the home page. This is why, as a minimum, Web browser software contains 'home', 'forward', and 'back' navigation buttons:

Home button	View your start page for exploring the Web
Forward button	Return to the page you visited before clicking 'Back'
Back button	Return to the page you just viewed

Where did it come from?

In 1989 Berners-Lee conceived an information-sharing 'web' space utilizing hypertext links (Fig. 1) to locate resources on a network [1]. He later suggested that resources on a network could be uniquely identified using an addressing scheme called a Universal Resource Identifier (URI) [2], an umbrella term that includes URLs (p. 11), and popularly known as an 'Internet address'. In a Web page the Internet addresses that underlie each hypertext link are usually identified by text that is a different colour and/or underlined. Aside from clicking on a hypertext link ('hyperlink') within a Web page, you can also type such an address directly into your Web browsing software, hit the enter key, and connect straight to that resource. In 1990 the first Web server and browser (i.e. client software) were developed, interacting via the HyperText Transfer Protocol (which is why URLs for Web sites begin with 'http://'). The first mainstream Web browser was called Mosaic and appeared in 1993. The popularity of the Internet soared because the Web was so easy to use, and in 1994 the World Wide Web Consortium (W3C) was established by Berners-Lee to guide the Web's future:

http://www.w3.org/

Web browsers

Mosaic was further developed by Netscape Communications Corporation into Netscape Navigator, and by Microsoft into Internet Explorer. These are the two most popular clients, but there are a number of alternative browsers for most computing platforms. Modern Web browsers manage

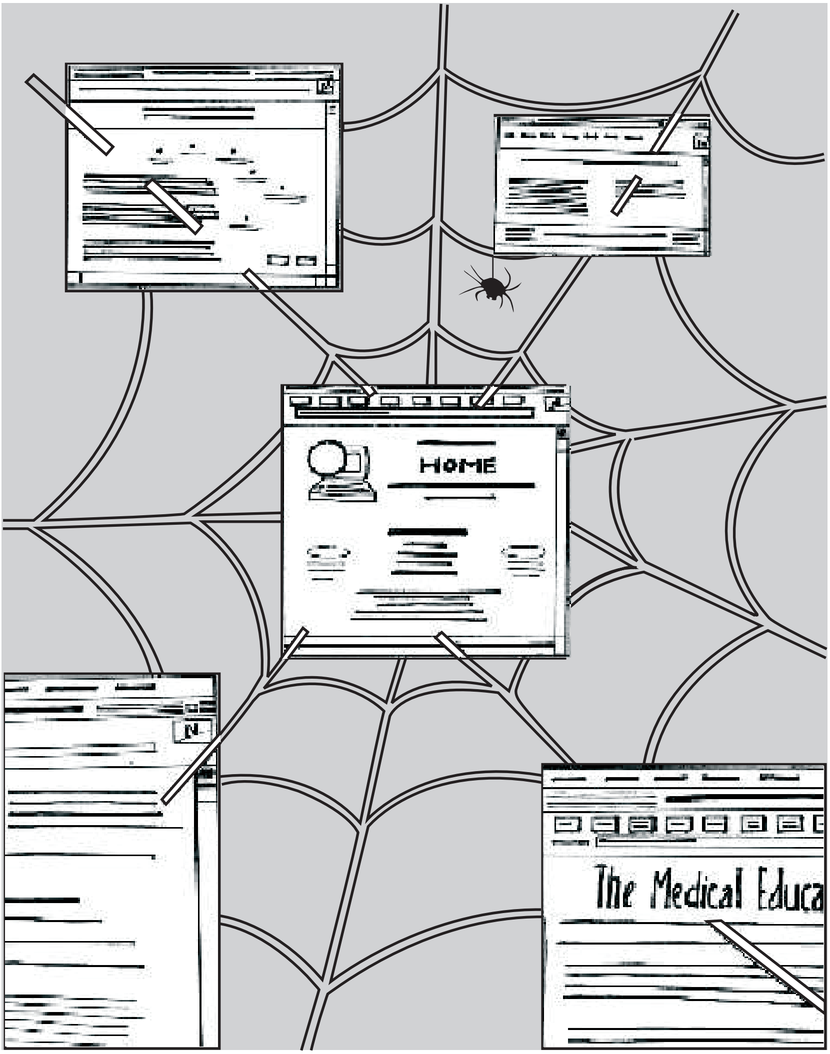

Fig. 1 Hypertext links weave the World Wide Web. To move from page to page, users need only point-and-click with a mouse. Each page may contain text, pictures, sounds, animations, computer files, or interactive mini-programs.

to provide the functionality of many other Internet services (p. 8) in one simple point-and-click interface. Because browsers share a common heritage, the user interface is essentially the same across all platforms and individual clients. Likewise, despite the use of proprietary technologies that resulted in a 'features war' in the late 1990s, a given Web page looks similar irrespective of the program or computer type being used to access it.

Netscape Navigator:
http://home.netscape.com/

Microsoft Internet Explorer:
http://www.microsoft.com/ie/

The basic task of any Web browser is to interpret HyperText Markup Language (HTML; see Box 2). HTML documents are retrieved from the server and interpreted by the browser. Images and any other page elements are likewise retrieved and loaded by the browser to create a complete Web page. If a page element is in a file format that your browser cannot handle internally, it will need help to view/play the file. Sometimes external 'helper applications' are launched alongside your browser when these types of file are encountered (e.g. programs to expand compressed file archives). Alternatively, 'plug-ins' turn your Web browser into a versatile multimedia player. Plug-ins are similar to helper applications in that they enable us to handle a variety of file types—but they do this seamlessly from within the Web browser itself. Common file formats you will come across on the Web are given in Table 1.

Box 2 What is HTML?

HyperText Markup Language (HTML) is used to create hypertext pages that can be viewed on different types of computer. A 'markup language' is a standard set of rules (a syntax) for bringing structure and meaning to parts of a document. HTML documents are typically indicated by an .html or .htm extension to the file name.

HyperText Markup Language (HTML):
http://www.w3.org/MarkUp/

HTML uses 'tags' to mark-up particular segments of text. These tags are analogous to the annotations a copy-editor might make on a manuscript (e.g. <h1>Top-level heading</h1>). As HTML originally focused on the *structure* of documents, there are tags to indicate relative heading sizes, paragraphs, lists, and links, etc. HTML was never intended to confer *meaning*—that's the job of XML (see text). Nor was it intended to control the *presentation* of information, as this was supposed to be up to the browser used to view the document. However, HTML's inflexibility lead to the creation of new tags that gave designers greater control over the presentation (font, colour, spacing, etc.) and layout (tables, frames) of their Web sites, and a way to interact with users (fill-in forms). Cascading style sheets (CSS) were an attempt to separate much of the complex presentation tagging from the document structure once again.

Web Style Sheets:
http://www.w3.org/Style/

Table 1 Common file formats on the Web

Category	**File suffix**[1]	**File format and viewing suggestion**[2]
Text	.html or .htm	HyperText Markup Language (HTML); Web browser
	.txt	Plain text file; Web browser, text editor, or any word-processing application
Applications	.pdf	Portable Document Format (PDF); Adobe Acrobat Reader or Web browser (with plug-in)
	.doc	Microsoft Word document; Microsoft Word or compatible viewer[3]
	.rtf	Rich Text Format (RTF); any word-processing application
	.ppt	Microsoft PowerPoint presentation; Microsoft PowerPoint or compatible viewer
	.exe	An executable (i.e. you can run it) PC program[3]
Images	.gif	Graphics Interchange Format (GIF); Web browser
	.jpg or .jpeg	Joint Photographic Experts Group (JPEG); Web browser
	.png	Portable Network Graphics (PNG); Web browser
Audio	.wav	Waveform-audio (WAV) file; Windows Media Player or Web browser (with plug-in)
	.mp3	Moving Picture Experts Group (MPEG) Layer 3 Audio; Windows Media Player
	.ram or .rm	RealMedia metafile or clip; RealPlayer or Web browser (with plug-in)
	.au	Sun Audio Format (includes μ-law); Windows Media Player or Web browser (with plug-in)
Video	.avi	Video for Windows; Windows Media Player or Web browser (with plug-in)
	.ram or .rm	RealMedia metafile or clip; RealPlayer or Web browser (with plug-in)
	.mpg or .mpeg	Moving Picture Experts Group (MPEG); QuickTime Player or Web browser (with plug-in)
	.mov	QuickTime Movie; QuickTime Player or Web browser (with plug-in)
Animation	.swf	Shockwave Flash file; Shockwave or Flash Player (plug-in)
	.gif	Graphics Interchange Format (GIF); Web browser
Archive	.zip	PC ZIP archive; WinZip
	.sit	StuffIt archive; StuffIt Expander
	.tar	UNIX 'Tape ARchive'; WinZip
	.gz	Gnu ZIP archive; WinZip

1 A file suffix (extension) is an acronym at the end of a file name (after the dot), typically giving a clue as to the file type or program that created it.
2 Other viewers/players may be available; many players include plug-ins.
3 Beware of viruses; see Chapter 3.4.

Several developments have resulted in a Web that is much more exotic than the original Web of the early 1990s. These include Java applets (mini-programs imbedded into Web pages), JavaScript, 'dynamic' HTML, and 'push' technology Web channels (see the Glossary for brief descriptions). Refer to the documentation that came with your Web browser, or purchase a general guide book, if you need help understanding the features of your software.

Copying and citing Web resources

Electronic copyright

Under the Copyright, Designs and Patents Act 1988 [3], copyright is automatically attached to any original work created by a qualifying author (or published in a qualifying country). Not everything can be protected by copyright, however, notable exceptions being facts and ideas themselves—although the selection of facts and the context in which these ideas are expressed will be protected in the UK. Copyright, giving the owner (subject to limited statutory exceptions) the sole right to copy, publish, modify, or publicly display a work (or to authorize another to do so), commences as soon as the work is recorded in writing or otherwise. These rights generally last for the period of life of the author plus seventy years.

Some material is available on the Internet without the consent of the copyright owner. The use of this material is a violation of the copyright attached to it. Even if literary materials (including the content of a Web page or e-mail message), software, or images, etc. do not originate in the UK, international copyright conventions make the use of them without the owner's consent unlawful within the UK.

You may wish to download and use medical software obtained via the Internet. Licence agreements that describe terms of use may allow you to do this (see Box 3). Similarly, a notice will often accompany literary copyright material setting out the uses, which the author permits, and those that would constitute a breach of copyright.

The Copyright, Designs and Patents Act provides for certain permitted acts in relation to copyright works including 'fair use' for the purposes of criticism and review, reporting current events, research, and private study, as well as copying for educational purposes and by librarians. What uses are considered 'fair' depends on such things as the nature of the use, what proportion is to be copied, and whether doing so damages the commercial potential of the original work.

Box 3 Downloading medical software

Free software

Software made available for anyone to use, copy, and distribute with or without making modifications (therefore requiring the source code). Source code, the instructions for building a program, must first be 'compiled' (converted from human-readable form into binary code) before it can be run on a particular platform. So long as the source code itself is made available free of charge (e.g. by downloading it) and the freedom to distribute modifications to the source is preserved, a fee may be charged by the distributor (e.g. to cover a compiled version, manual, or CD-ROM). This type of licensing arrangement is broadly referred to as 'open source' (see http://www.opensource.org/), although there are other flavours of free licence such as the 'copyleft' terms of the Free Software Foundation (see http://www.gnu.org/).

Freeware

An ill-defined term sometimes used for gratis software that cannot legally be modified and is not distributed with source code, so it is not considered 'free software'.

Public domain software

A category of software where the author does not exercise copyright. Such software may be modified without permission.

Shareware

A category of software that users can try out for a specified evaluation period before buying it, as required by the terms of a user licence. An extremely popular method of distributing software on the Internet.

Citation of online sources

Although the importance of citing online sources had been recognized as critical to the development of the Internet as a viable tool for medical communications, and interim guidance was available [4], it was not until 1997 that limited 'official' guidance for medical authors was provided in 'Uniform requirements for manuscripts submitted to biomedical journals' [5]. An adaptation of the Vancouver style, the suggested syntax for online journal articles takes the following form:

> Barrie JM, Presti DE. Digital plagiarism—The web giveth and the web shall taketh. *Journal of Medical Internet Research* [serial online] 2000 Mar [cited 2001 Jul 26];2(1):e6. Available from: URL: http://www.jmir.org/2000/1/e6/

Citing Web pages and other Internet sources presents a number of unique challenges [4]:

- The importance of retaining location descriptions 'generic' to the particular information sources is well established [6]. In the case of

Internet resources, the generic location description is the Internet-standard URL.

- Articles that are transient or dynamic (updated or revised in an ongoing process) typify the Internet, and underline the value of specifying a citation date. It remains to be seen whether the scientific community will accept the validity of non-permanent documents as legitimate references, as the ability to consult these exactly as cited is paramount to the process of peer review. In the absence of a paradigm shift, it may be that only archived, retrievable versions are regarded as valid. Version or revision numbers, the online equivalent of edition, are commonly used in Internet archives and may be cited in a similar way.
- Page numbers are not usually a feature of electronic documents, as pages will change depending on the viewing method. The same applies to the number of screens used to display the information.
- Interpersonal e-mail can be cited as a personal communication (with due regard for the author's copyright), without being mentioned in a reference list.
- E-mail messages on mailing lists and in newsgroups present a particular problem. Both types of message have unique message IDs but these are of little help, although mailing lists are more likely to have retrievable archives than newsgroup items. The transience of such articles may invalidate them as means of recording academic communications.

Addressing information inequalities

The Web undoubtedly has a positive role to play in improving access to healthcare information (see also Chapter 5.1). Two important reasons for unequal access to this (and other) information are disability and poverty. The Web can contribute to, and help overcome, both these barriers.

Disability

The Web (and Internet in general) may have a special role to play in the communication of healthcare information and provision of support for persons with sensory or physical disabilities (see Table 2). However, the poor design of some Web sites can conversely marginalize patients unable to use technology or features optimized for a non-disabled audience [7]. The W3C's 'Web content accessibility guidelines' are designed to help make Web content accessible to people with disabilities:

http://www.w3.org/WAI/

Table 2 The Internet provides access to health information and support in disability

Impairment	Solution
Hearing	Written information is the mainstay of the Web (and available via e-mail, newsgroups, etc.)
Speech	E-mail can be used by people with speech impediments (e.g. motor neurone disease) to request information or to communicate with health professionals
Vision	Web browsers may permit users to increase the base-size of displayed type (as may various computer accessories); 'text-to-speech' software is an option if reading is difficult
Physical	Electronic access to online libraries, banking, and shopping, etc. may allow greater independence from support services or carers

Another W3C activity relates to the use of speech recognition and synthesis as a basis for Web site interaction (of potential benefit to both disabled and illiterate users):

http://www.w3.org/Voice/

For information about other accessibility initiatives for persons with disabilities, see the Internet Society Web site:

http://www.isoc.org/isoc/access/

Health information poverty

Developing countries, and many members of society within developed countries, do not have equal access to Web-based information; they represent the so-called 'digital divide':

Digital Divide Network:
http://www.digitaldividenetwork.org/

Internet Society:
http://www.isoc.org/internet/issues/divide/

For example, in the UK high-income and social grade AB homes are around three times as likely to have Internet access as DE-grade and low-income homes [8, 9]. The international picture is even more revealing [10]:

- A month of Internet connectivity costs 1.2% of the average monthly income in the US, versus 278% in Nepal.
- Fifty-four percent of the US population are Internet users, versus 0.4 percent of the populations of sub-Saharan Africa and South Asia.
- The 'global' Internet is accessible to just 6.7% of the world's population.

Eysenbach observes that '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.' [11]. Even so, many commercial healthcare enterprises like to be seen as having an ethical conscience, sometimes on the basis of branding if not for reasons of moral integrity. Consequently, there are a number of policy-driven and privately funded initiatives seeking to bridge the divide. Major initiatives can be tracked via the United Nations Educational, Scientific and Cultural Organization (UNESCO) Web site:

Observatory on the Information Society (UNESCO):
http://www.unesco.org/webworld/observatory/

Although some publishers have consented to allow developing nations free access to leading medical journals [12, 13], this doesn't address a major impediment to information access—the availability of low-cost technology for browsing the Web [10]. Furthermore, health information must be relevant to the population requiring it, yet little health research from developing countries is published [14, 15]. The developed world must not forget to ask researchers in the developing world what the problems are and how they might be addressed; access to health information is only one of several barriers to information exchange across the divide [15]. We should be equally concerned about getting information out as we are about getting information in.

There are other (often related) barriers to information access, including gender, ethnic origin, and age. Attempts to break some barriers, such as language, are being made using technology itself (e.g. AltaVista's Babel Fish translator):

http://www.altavista.com/

On the horizon

The chapters that follow document the enormous potential of the Internet to positively impact upon the delivery of healthcare. Such potential seems sure to outshine various postulated negative health consequences such as Internet addiction disorder [16], sexually transmitted infection risk [17], the facilitation of suicide [18] and Münchausen [19] behaviours, or 'cyberhypochondria' [20].

It isn't easy to predict what the Web may look like tomorrow, or exactly how it will be used in healthcare environments. Looking at the goals and operating principles of the organization charged with evolving it—the W3C, can provide some (albeit technology-focused) insight:

http://www.w3.org/Consortium/Points/

More practical insights can be gained by observation of trends already in progress. The Web is integrated with a variety of hardware (not just PCs), such as telephones, TV, and handheld devices—allowing us to browse with or without wires. More people—able and disabled, rich and poor—are participating in the information revolution. Web content is increasingly interactive (e.g. via Java) and increasingly personal (e.g. via customized home pages) as sites vie for our attention. There is more multimedia online, particularly streamed audio and video (i.e. played back during download). New versions of the applications we use—word processing software, personal organizers and the like—often incorporate Web functionality (e.g. saving to HTML). It is becoming easier for 'ordinary' people to publish to the Web instead of merely viewing it. Solutions to ensure the privacy of our personal communications and to deliver secure data exchanges are becoming easier to implement and use. It is getting easier to find, filter, and validate information on the Web, as automated software tools get better at interpreting it.

Machine-readable XML

The Web we know today is based on HTML, a syntax optimized to structure (and latterly, display) hypertext information in human-readable form. 'eXtensible Markup Language' (XML) is the next step along the path to machine-readable information, using a syntax (like HTML) to tag individual bits of information:

http://www.w3.org/XML/

Although HTML predefines the syntax used and the number of tags (see Box 2) is fixed, the meaning of syntax in XML depends on the meaning the document author chooses to give it. In other words, XML is extensible (hence the name!), as new tags can be devised *ad lib* to fit the author's needs. You could define tags to indicate useful information such as diagnosis, allergy, haemoglobin, etc. (cf. the 'paragraph' tag of HTML, for example, which confers structure not meaning). This may sound a bit complicated, but it's a very important difference; an example helps illustrate this (see Box 4). XML has been identified as essential to the sharing of healthcare data between computer systems in the NHS [21].

Box 4 The difference between HTML and XML

Consider the following clinic letter in HTML (extract only):

<p>Patient: Joe Bloggs DOB: 1968 Oct 13</p>

<p>Diagnosis: Asthma</p>

<p>This patient with asthma was seen in Asthma Clinic today. His asthma is now stable and we are returning him to your care.</p>

A browser will display this information in three paragraphs, with the words 'Patient:', 'DOB:', and 'Diagnosis:' displayed in bold. What you see is all you get. Humans can read and understand it. Computers can display it on-screen, but they cannot 'read' any meaning from it.

Now consider the same letter in XML (extract only):

<patient>
<firstname>Joe</firstname>
<lastname>Bloggs</lastname>
</patient>
<birthdate>
<year>1968</year>
<month>Oct</month>
<day>13</day>
</birthdate>
<diagnosis>Asthma</diagnosis>
<clinicnote> This patient with asthma was seen in Asthma Clinic today. His asthma is now stable and we are returning him to your care.</clinicnote>

To humans, this information might look the same on-screen as it would in HTML (using a separate style sheet that tells the browser how each element should appear on-screen). Aside from displaying it, a computer can now derive meaning from the XML-encoded information as well (i.e. it has become machine-readable). A computer can, in a sense, 'know' that the patient's first name is Joe, and that Joe was born in the month of October, etc. It can take this meaningful information and manipulate it as instructed, e.g. import the clinic note and diagnosis into the corresponding data fields in Joe Bloggs' electronic patient record. HTML can't do this; it can't identify what the information it has marked-up and displayed means.

But what if the general practitioners' clinical system doesn't have a field for 'diagnosis', for example? Well, <diagnosis>Asthma</diagnosis> could be automatically mapped to <disease>Asthma</disease> (or whatever) using a simple translation program. Furthermore, the program 'knows' that other occurrences of the word 'asthma' in the document are incidental. Because these other mentions don't appear in the context of <diagnosis>, the program won't attempt to record each additional occurrence as a new diagnosis (as a program that merely scans HTML looking for keywords might).

It offers a truly universal text-based exchange format for structured data (i.e. interoperability); this represents the Holy Grail of electronic data interchange (EDI).

XHTML and metadata

HTML has been redefined as XHTML, a practical application of XML that continues to convey human-readable information on the Web. To help make the Web understandable to machines, XHTML can be combined with other data in XML format—such as Web site content or accessibility ratings, privacy information, data to be retrieved by search engines, and other types of metadata ('data about data'—p. 206). This 'Semantic Web' [22] is described by the W3Cs integrated 'Resource Description Framework':

> eXtensible HyperText Markup Language (XHTML):
> **http://www.w3.org/MarkUp/**
>
> Resource Description Framework (RDF):
> **http://www.w3.org/RDF/**

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2 Using the Internet to communicate

Communicating with colleagues

- The Internet can facilitate communication with colleagues at international, national, and local levels. Using e-mail or the Web can have disadvantages as well as advantages.
- UK healthcare institutions are realizing the potential of the Internet to communicate information to large groups of health professionals in a timely and cost-effective manner. The Internet also promotes flow of information from the 'bottom up'.
- Some hospitals publish information about their services (e.g. waiting times) on Web sites accessible to local colleagues in primary care. Patient-specific information is not generally communicated via the Internet at present.
- There are various ways to make your Internet communications with colleagues more efficient.
- Communicating with colleagues online about patients raises a number of ethical issues. There are advantages and risks for both patient and doctor.

Communicating with patients

- Internet-enabled consumers have accelerated the demand for electronic mail (e-mail) access to healthcare providers. At some point e-mail will be as ubiquitous as the phone and fax.
- E-mail is most appropriate where an established doctor–patient relationship exists. E-mail correspondence with anonymous persons may carry risk of misunderstandings, ambiguous therapeutic responsibility, and malpractice; it is not recommended.
- E-mail communication with patients requires attention to etiquette, medico-legal prudence, and administrative process re-engineering.
- E-mail can be advantageous in streamlining office workflow and improving communication with patients. Disadvantages may be increased administrative overhead in the initial stages of implementation and lack of reimbursement for time spent.
- New stringent security standards for electronic exchanges will affect technical requirements of e-mail software.

continued

- Commercial clinical communication programs generally provide secure messaging, options for mail routing to various clinical workers, triage capabilities, and sometimes templates for 'cybervisits'—medical consultations in lieu of office visits.

Communicating in groups

- The Internet provides exciting opportunities for using and extending the use of small-group techniques in both educational and problem-solving activities.
- The basic principles of effective group work apply equally to an online environment, although there are some areas in which online groups differ crucially from face-to-face equivalents.
- Technological considerations can be an important barrier to effective group work. 'Lowest common denominator' technology is an essential principle.
- Whereas the basic social skills needed for effective face-to-face communication have generally been learnt at mother's knee, participants in an online group must learn a whole set of new cues and techniques ('netiquette') to support effective communication.
- One important pedagogical advantage of online group work over the face-to-face equivalent is that asynchronous communication allows time for reflection upon the contributions of other members. The reticent or under-confident member can construct a considered response while offline.

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2.1 Communicating with colleagues

Bruce McKenzie and Adrian Midgley

Electronic communication in healthcare is very much on the UK political agenda and there are compelling social and professional reasons to 'go electronic'. The change to a preference for using electronic media for communications has a number of implications for doctors as a result of the prevailing expectations of Internet users (see Table 1). The virtues of e-mail in simplifying communications between medical colleagues, however, outshine the potential disadvantages of the medium (see Box 1) and contribute to its uptake. In this chapter, we consider how e-mail and the Web can foster communication between colleagues internationally, nationally, and locally, with national institutions, and between primary and secondary care.

Table 1 Expectations of Internet users and implications for doctors [1]

Expectation	Implication
Communications will be faster due to rapid electronic transmission	Pressure to respond to e-mail will increase
There is a potential for rapid electronic reproduction and distribution of messages	Confidentiality can easily be breached
E-mail is considered informal and unlikely to be read by anyone other than the intended recipient	Since monitoring and recording of communications is possible, unencrypted e-mail (p. 132) should be considered equivalent to a letter that may be 'intercepted' by a secretary
Improved access to global electronic publications and colleagues will increase the volume and sources of information available	A strategy to determine the relative value of different information types is required (see Chapter 3.1)
New software and hardware will be introduced regularly	Doctors must be prepared to adapt in order to benefit from new technology

Box 1 Using e-mail to communicate with colleagues

Potential advantages

- Speed
- Low cost
- Efficiency (e.g. easy to contact published 'authorities')
- Documentation of advice, etc.
- Minimizes interruptions
- Message threading (p. 79) allows the reader to monitor multiple conversations
- Asynchronicity (p. 78)

Potential disadvantages

- Using e-mail requires training
- Pressure to reply soon
- Impersonal
- Misinterpretation (see Chapter 2.3)
- Insecure (unless encrypted: see Chapter 3.4)
- Easy to ignore

Communication with international colleagues

The opportunity to bring together geographically dispersed health professionals afforded by online forums and discussion lists promises multidisciplinary co-operation as never before. Most Internet mailing lists, newsgroups, and Web-based forums cater to an international audience. Many of these resources are specific to individual specialities or topics. While promising a wealth of experience, they also introduce the nuances of differing cultural, financial, political, and regulatory backgrounds; what is applicable or acceptable in medical practice in one country may not be so in another. Examples of international forums include:

Fam-Med mailing list:
http://fpen.org/fam-med

'sci.med' newsgroup:
nntp://sci.med

The heart surgery forum:
http://www.hsforum.com/forum/

Communication with national colleagues

National forums are ideal for debating issues pertaining to the country in which you practice. A wider audience is perhaps less likely to be interested in the politics of your own health service, working conditions, official communications, or clinical practice guidelines. Web sites are a popular means of communicating on a national level and, like e-mail, have a number of advantages and disadvantages over paper-based alternatives (see Box 2). Examples of national forums for UK doctors include:

GP-UK mailing list:
http://www.jiscmail.ac.uk/lists/gp-uk.html

Doctors.net.uk:
http://www.doctors.net.uk/

UK Practice.net:
http://www.ukpractice.net/

Such Web resources may be open to the public, or may require registration to permit access to restricted areas according to the needs and wishes of the forum users (see Fig. 1).

Box 2 Using the Web to communicate with colleagues

Potential advantages

- Bypass much of the delay in traditional publishing (see Chapter 7.1)
- International or password-protected local access as appropriate
- Ease of use
- Ease of updating
- Interactivity of online forums
- Searchable
- Cost-effectiveness
- Integration with a variety of multimedia resources
- Asynchronicity (p. 78)

Potential disadvantages

- Dependence on technology and expert skills
- Low screen resolution compared to print
- Easy to ignore

Communication with local colleagues

It is rare that all the members of a committee or craft assemble for briefing or discussion. So-called 'telephone tag' soaks up an unreasonable amount of time and adds pressure to busy working lives. Meeting time is not best used to read papers. Paper communication rarely reaches the right person at the right time, and commonly cannot be found when it would be useful [2, 3].

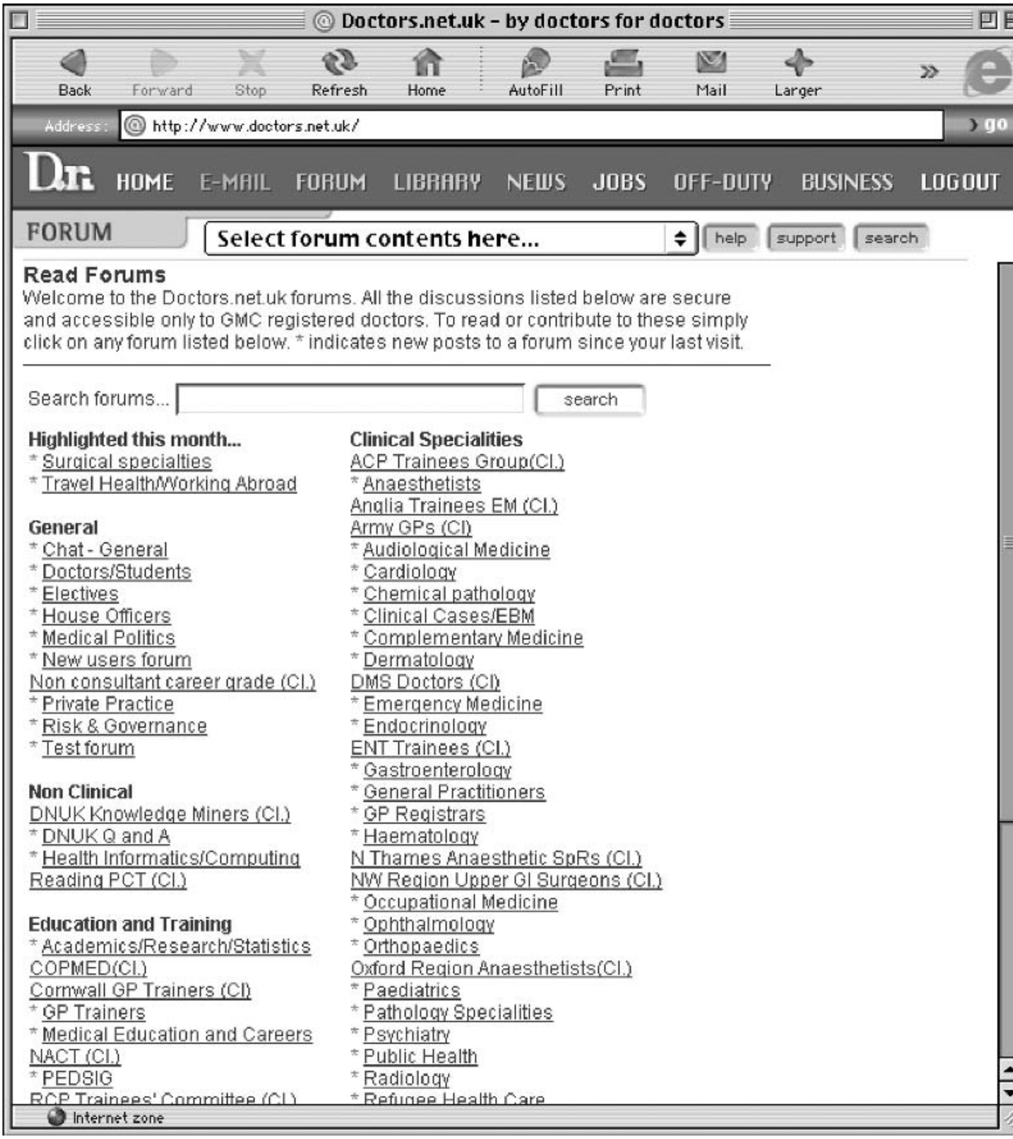

Fig. 1 Some sites, such as Doctors.net.uk, require registration in order to provide a closed forum for professional discussions.

E-mail rarely replaces the persuasive power of a face-to-face meeting or the friendliness of a voice call, but an e-mail conversation can be more effective and timely—particularly if there are complex factual matters to consider. A document placed in a shared workspace (e.g. on a Web page) and found at the time someone is thinking about the topic may be more persuasive than a direct approach at the wrong time. Search engines on the Internet (or intranets—p. 15) make ideas and background reading more accessible than most paper filing systems.

In the NHS the advent of Primary Care Groups (PGCs) and Primary Care Trusts (PCTs) has promoted closer working between general practices and other local community services. PCG/Ts can use a public Web site as a communications hub for disseminating information to interested stakeholders. This might include, for example:

- A description of organization structure and personalities.
- Meeting agendas and minutes.
- Local developments.
- Business plans and annual reports.
- Consultation documents.
- Details of GP practices within the organization.
- Local policies (such as the Health Improvement Programme).
- Patient information, etc.

Examples of PCT Web sites include:

Airedale PCT:
http://www.airedale-pct.nhs.uk/

North East Lincolnshire PCT:
http://www.nelincs-pct.trent.nhs.uk/

Similar objectives can be achieved by Local Medical Committees (LMCs), which represent local groups of general practitioners. Examples of LMC Web sites include:

Glasgow Local Medical Committee:
http://www.glasgow-lmc.co.uk/

Devon Local Medical Committees:
http://www.devonlmc.org/

Individual practice Web sites primarily serve to enhance communication with patients (and prospective patients). The potential role of such sites (and communicating with patients by e-mail) is considered briefly in Chapter 2.2.

Communication with national institutions

The potential of the Internet as a means of disseminating communications to large groups of health professionals is enormous. This has been realized by the majority of significant healthcare institutions in the UK, driven in part by the efficiency of the Internet in one-to-many communications and by widespread Internet access via NHSnet (p. 16). Rather than printing and mailing out (at great expense) multiple copies of bulky documents, the 'For further information, see our Web site' approach helps to reduce the deluge of paper. It also helps ensure that these documents can be found when required. UK national institutions that use the Web to disseminate information include:

Department of Health:
http://www.doh.gov.uk/

National Institute of Clinical Excellence:
http://www.nice.nhs.uk/

British Medical Association:
http://www.bma.org.uk/

Royal College of General Practitioners:
http://www.rcgp.org.uk/

Interactive online working groups, both clinical and managerial, facilitate bottom-up working practices in traditional top-down hierarchical health services. In the UK, rather than being simply a medium for transmitting medical records and laboratory results, etc., NHSnet provides the infrastructure necessary to achieve such ambitions by allowing health service staff access to e-mail and the Web. Important obstacles to the open publication of feedback from the 'bottom', however, are the suppression of non-conformist views and fear of being liable for offensive opinion or content.

Increased use of electronic communications to disseminate information rapidly (via the Internet, NHSnet, or other services) might have avoided public and professional dissatisfaction with the Department of Health's handling of various health scares in the UK (e.g. oral contraceptive safety, or the safety of British beef). Although we are not aware of any studies reporting the efficacy of electronic communications in such 'medical alert' situations, it has been shown to improve the speed of and satisfaction with communication in relation to laboratory and discharge reports sent from hospitals to general practitioners [4].

To improve the dissemination of electronic information to doctors in the UK, the Department of Health and the National Institute of Clinical Excellence are working in partnership with Doctors.net.uk, a popular Internet portal for UK doctors. Doctors.net.uk members receive official bulletins and guidelines via e-mail (any UK doctor can register for a free account):

http://www.doctors.net.uk/

Communication between primary and secondary care

The Internet could help break down barriers between primary and secondary healthcare by improving communications between workers in these sectors. In the UK a number of NHS hospitals have developed Web sites that serve this function. These sites may include non-confidential information targeted at doctors in primary care, such as:

- Information about the range of local hospital services.
- Advice from local specialists (e.g. recognizing malignant skin lesions).
- Particular interests and backgrounds of local specialists.
- Infectious disease alerts (e.g. MRSA outbreaks).
- Waiting times for outpatient assessments and inpatient procedures.
- Referral and other protocols.
- Local newsletters or magazines, etc.

Sensitive information, such as laboratory and radiology results, or online appointment bookings, would require additional security measures (such as SSL, p. 133) or transmission via NHSnet (p. 16). This type of patient-specific communication is ordinarily an adjunct to clinical information systems, which are discussed in Chapter 3.2.

Brighton Health Care NHS Trust became the first of many non-teaching hospitals in the NHS to introduce a presence on the Web, in December 1994 (although it has since moved from its original Web site):

http://www.rsch.org.uk/

The Web sites of other UK hospitals and local NHS services can be accessed via the NHS Web site:

http://www.nhs.uk/

Efficient communication on the Internet

There are various ways to make your Internet communications with colleagues more efficient. Being efficient can make the difference between technology working for you or against you!

General

- Interpersonal e-mail, mailing lists, and the Web are best used in combination, with indexed repositories ('document warehouses') and search engines (see Chapter 6.2) replacing the current habit of posting documents to large lists of people.

- If you have dial-up Internet access, compose and read e-mail messages offline to avoid blocking your telephone and to minimize call charges. Web pages can also be saved for offline reading.

Interpersonal e-mail

- The best way to find someone's e-mail address is to ask for it.
- Your institution may have its own directory (e.g. NHSnet's Address Book Service).
- Online public address directories are largely unhelpful.
- A 'lifelong' e-mail address keeps you in contact should you change jobs, location, or Internet service provider (e.g. Hotmail, Doctors.net.uk)
- Include alternative contact details (e.g. telephone number) in a signature.
- Use the 'rules' feature of your e-mail client to manage e-mail if you receive a lot of it (e.g. automatically sorting messages into different folders, etc.). Consult the documentation that came with your client for help with this feature (if present).

Mailing lists

- Subscribe to relevant lists by recommendation.
- Consider using a filter, if available, to receive lists messages pertaining only to specific topics.
- Make use of keyword searches of the list archive, if available.
- Use the 'digest' option, if available, to reduce the number of daily, weekly, etc. messages on high-volume lists.
- Moderated (supervised) lists are often lower volume and more tightly focused than open lists.
- If a list is especially verbose or otherwise problematic you'll want to unsubscribe; make sure you record how to do so.

Newsgroups

- More useful to patients seeking support than time-limited doctors; think before you post and risk subjecting your e-mail address to spam (unwanted e-mail, p. 31).
- Consider using a filter to receive articles pertaining only to specific topics.

Web-based sites

- Restricted-access forums are more likely to retain a tight focus.
- Forums that support message threading (p. 79) make for efficient navigation.

- Unlike mailing lists you don't have to scan through every message, but can choose those of potential interest from the subject line.
- Because Web forum replies are composed online, they can be hastily typed. Typing into a spell-check enabled word processor and then pasting into a Web-form can reduce embarrassment!

Ethical issues

Some Web sites and mailing lists offer closed (non-public) forums where doctors can discuss medical matters without fear of misinforming (or frightening) the public. It would seem reasonable to share information pertaining to individuals with other health professionals when the patient stands to benefit from shared knowledge and experience: this is how we learn. Validation of professional status is, however, commonly far from stringent (if required at all). In this setting, doctors must be especially careful not to disclose personal health information even with the well-meaning intention of sharing experience or seeking clinical help.

If identifiable personal health information is to be shared in an e-mail message to a colleague or online forum, the patient's express and informed consent must first be sought. If the patient is not identifiable, the patient's express consent is not a prerequisite (although a duty of confidence remains). The important issues of privacy, confidentiality, and consent are discussed further in Chapter 3.4.

Professional online forums for doctors may include requests for help in making a diagnosis or planning treatment. The giving and receiving of professional advice online can be fraught with risks for both patient and doctor for several reasons:

- Misinformed advice from other 'doctors' may promote unnecessary invasive procedures, or cause morbidity or even mortality, making it essential to verify (authenticate) the status of the person giving the advice [5]. There is presently no easy way to do this on the Internet.
- The advising physician will not usually interview or examine the patient concerned at a future date.
- The advising physician will not usually have access to any medical records of the patient concerned.
- Because e-mail messages are usually brief, the poster may omit important details.
- An asynchronous online dialogue does not readily permit interactive questioning, as does a real-time conversation.

Consultation over live video links (see Chapter 3.3, Telemedicine) remains experimental in the UK but may help overcome some of these concerns. A number of doctors have taken to appending disclaimers to their electronic signatures to lessen the risk of legal action resulting from erroneous advice given online. An alternative approach is not to reply directly to questions, but rather to recommend an information resource (such as published guidelines on an authoritative Web site, or to cite references that can be used to verify an opinion). If there is to be an ongoing dialogue, it might be advisable to use private (perhaps encrypted—p. 132) e-mail messages to lessen the risk of an accidental breach of confidentiality, rather than continuing to post to a common forum. Ultimately, discretion rests with the individual doctor as to whether and how they should respond to these requests.

The issues around giving online medical advice directly to patients are considered in Chapter 2.2.

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2.2 Communicating with patients

Beverley Kane

Internet-enabled healthcare consumers have accelerated the demand for e-mail access to healthcare providers [1]. This trend is compelling healthcare providers, government agencies, consumer advocacy groups, and malpractice insurers to establish mechanisms and guidelines for such exchanges. While there are no controlled studies documenting the advantages, disadvantages, risks, or benefits of e-mail, there is a growing body of opinion and anecdotal experience that suggests proper usage. The first large-scale prospective study of doctor–patient e-mail is due for publication in late 2001 [2]. This evidence, coupled with standards of privacy for phone and fax messaging and by legal precedent for medical records, permits the formulation of guidelines for electronic communication. Several such sets of guidelines are available, emphasizing communication [3,4] and legal risk [5] for established patients [3,4] and unknown or anonymous [4–7] parties.

Recent developments as of this writing include the facts that:

- the clinical use of e-mail has tripled in the past three years;
- there is increased emphasis on security by popular demand and government regulation;
- there are numerous commercial products for facilitating secure, triaged provider-to-patient e-mail in a clinical setting.

Established patients or unknown correspondents

E-mail usually comes from patients with whom the provider has an established, face-to-face relationship. However, it can also come from a person whom the provider has never met or spoken with. The unknown person might be the caretaker of an established patient, someone who serendipitously comes into possession of the provider's e-mail address, or a visitor to the provider's public Web site. Because 'xenograms' (mail from 'foreigners') present special legal and ethical challenges (see Box 1), this chapter pertains mainly to electronic communication in the context of established doctor–patient relationships. Written from an American perspective, the issues described have global relevance.

> **Box 1 Liability outside established relationships**
> Health professionals may also be liable for advice given online outside the context of an established doctor–patient relationship. Such advice may be dispensed—even if not intended—on mailing lists, newsgroups, in personal e-mail messages, or on Web sites. It may be given in good faith, but either the patient or doctor could be fictitious. Analyses of the issues are available elsewhere [4–7] but pitfalls such as this have led various professional bodies to draft guidance in an attempt to address medico-legal and ethical concerns. For example:
>
> Consulting in the modern world (British Medical Association, 2001):
> **http://www.bma.org.uk/gpc.nsf**
>
> Providing advice and medical services online or by telephone (General Medical Council, 1998):
> **http://www.gmc-uk.org/standards/online.htm**

E-mail or secure messaging

The three main ways that patients can correspond with healthcare professionals are illustrated in Fig. 1. The first route is simple e-mail sent over the open Internet using a dedicated e-mail client with or without encryption options (built in, or purchased separately). Stand-alone encryption software (p. 132), such as PGP (Pretty Good Privacy) has generally proven too cumbersome for general use. Many Web browsers provide more convenient 'off-the-shelf' alternatives with built-in security features like SSL (Secure Socket Layer: see p. 133). The Verisign Corporation and other certifying authorities provide reliable authentication of communicating parties through digital certificates (p. 134) which often require in-person proof of identity. In addition, many Internet-based health companies and traditional health information systems companies offer proprietary protocols for secure messaging within a Web hosting service. These companies and organizations typically offer secure messaging as part of a free or low-cost group practice Web site or as part of their core practice management products. Patients send e-mail to the healthcare provider by logging onto the provider's Web site and following a link to the provider's messaging account. The messaging systems of Web hosting services generally provide a small but medically pertinent feature subset of full-featured e-mail applications.

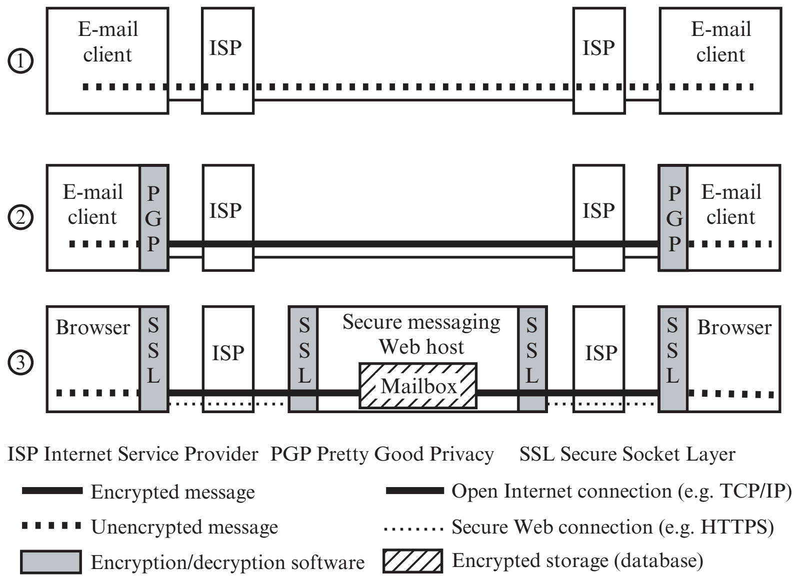

Fig. 1 From a security viewpoint, there are three main ways in which patients can communicate with their healthcare provider.

In addition, secure messaging systems may support *structured e-mail*—a set of templates that serve patients with forms to fill out. Forms are provided for such *demand management* functions as appointment scheduling, laboratory results, and billing questions. Structured message forms can be automatically routed to the appointment clerk, billing clerk, nurse, or physician.

As stringent government regulations loom, such as the US Health Information Portability and Accountability Act, healthcare providers are advised to use software that complies with the prescribed standards of privacy.

Most of the guidelines that follow apply equally to e-mail and secure messaging. The recommendations pertain to interpersonal dynamics between the clinician and patient, office workflow, and the observance of medicolegal prudence. The term e-mail is used generically for both technologies.

The nature of e-mail

From a sociological standpoint, e-mail is a hybrid between letter writing and the spoken word. From a technical standpoint, unencrypted e-mail is at risk through being less private than postal mail opened only by the addressee or telephone calls and voicemail taken directly, rather than broadcast from an answering machine speaker. In practice, e-mail replaces and is used more like the telephone—but with less urgency.

A consideration of the advantages and disadvantages of electronic mail in a clinical setting will help you decide whether it is appropriate to provide patients with your e-mail address. Bear in mind that not all communications with patients need involve interpersonal e-mail (see Box 2).

Box 2 Communicating with patients via Web sites

Not all communications with patients need to involve interpersonal e-mail. A practice/office Web site (see Fig. 2) could provide information or facilities such as:

- Surgery or clinic times, out-of-hours arrangements
- Information about services offered and staff members
- Special events or campaigns (e.g. flu immunization)
- Policies on emergency appointments and home visits
- Health promotion advice
- Self-help/over-the-counter remedies for simple ailments
- Fill-in forms for ordering repeat prescriptions or booking appointments
- Responses to health-related media stories
- How to make a complaint

Advantages of e-mail in clinical communications

E-mail potentially offers several advantages over existing communications channels between healthcare providers and their patients.

- Due to its asynchronous (back and forth over hours or days) nature, e-mail is less intrusive than ringing telephones. E-mail can be batch-processed more quickly than voicemail at the convenience of the recipient.
- The majority of phone calls to clinics are non-urgent. Patients with routine enquiries can be plagued by busy signals and voicemail systems with irksome branching menus, lapses on hold, and the threat of telephone tag. Many patients prefer e-mail for such communications [1, 8, 9].
- E-mail is a written record that removes doubt as to what was said. Often patients under duress forget to ask important questions. Verbal information might not be fully understood or recalled. E-mail follow-up allows clarification and retention of information provided in clinic. As a written record, e-mail should document that proper care was given.

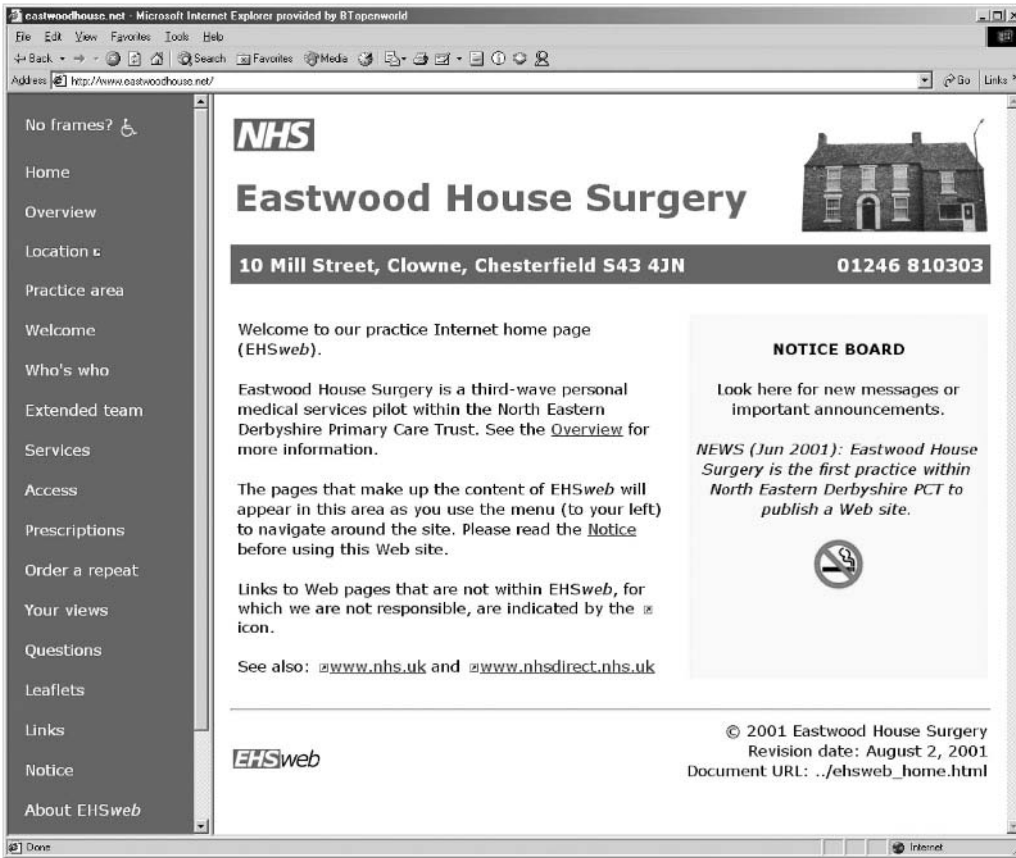

Fig. 2 A medical practice Web site provides information and support to patients or prospective patients.

- E-mail is especially useful for information the patient would have to commit to writing anyway. Examples include referral information, test results, and self-care instructions.
- E-mail can embed links to patient education materials on the provider's Web site or on Web sites of trusted sources, such as NHS Direct Online (p. 170).
- E-mail messages are less likely to fall through the cracks of a busy practice. Phone messages are often lost or illegible. Simple e-mail filtering systems and more elaborate Web-based routing systems can deliver messages to the appropriate person.
- E-mail messages can be more detailed than those left in voice mail boxes (especially systems with a 60-second limit) or taken down by an

amanuensis. E-mail tends to focus the sender's intent and avoids the rambling, multi-agenda phone call whose polite termination is difficult to manoeuvre.

- From an administrative standpoint, when e-mail has been established as the patient's preferred route of communication, appointment reminders, insurance questions, and routine follow-up enquiries lend themselves well to that medium.

Disadvantages of e-mail in clinical communications

Like any communication medium, e-mail can be abused and misused.

- Many practitioners are concerned that answering e-mail will further burden their overtaxed schedules, without the prospect of reimbursement for time spent online. In the US, a few insurers are offering or experimenting with reimbursing for 'cybervisits' [10]. In a capitated system (allocation of funds on a per-head basis), a cybervisit may obviate the need for an office/surgery visit, thus saving money for the health plan and time for the patient. There is evidence that patients themselves will be willing to pay a fee to get advice from their doctors [8, 9]. In the early stages of adoption, or in single-handed and small practices, physicians might be responsible for their own e-mail. Administrative support might be weak or non-existent.
- Some patients might become long-winded and frequent correspondents.
- When the volume of e-mail reaches critical mass, it might be necessary to retrain existing personnel or hire additional support to handle the load.
- E-mail systems may not provide confirmation that the message was delivered, although most mail servers notify the sender if a message could not be delivered to the recipient's mailbox. Even software that returns a receipt saying the message was 'read' can only certify that the message was opened. It cannot assure that the message was actually read and understood.
- For novices, uncertainty exists around netiquette (p. 76) and other subtleties of correct usage. Some clinic–patient relationships will not tolerate a trial-and-error approach to the electronic persona.
- The medico-legal standing of e-mail-based communications has not yet been established clearly (see 'Administrative and medico-legal guidelines' below). Local laws and customs might vary widely. Some jurisdictions consider e-mail consultations across licensure boundaries to be practicing medicine without a license [4].

- The electronic medium poses unique issues relating to security and privacy (see Chapter 3.4).

Communications guidelines

In these times of increasingly impersonal, truncated, and regulated care, clinic time with patients is often compromised. E-mail facilitates an ongoing caring relationship. If you anticipate a need to re-contact the patient with regard to test results or other near-term follow-up, you should always enquire about the patient's communication preferences.

Informally, you can ascertain preference for e-mail, voice mail, or postal exchange at the time of visit and document this in the chart. A more formal arrangement entails obtaining informed consent [4]. Patients might elect telephone, e-mail, or the postal route at different times for different purposes. You should confirm on a visit-by-visit basis which route to take. At that time you should:

- Ascertain how often both parties retrieve e-mail and establish a maximum turn-around time for patient-initiated messages. E-mail should be checked at least three times a day—first thing in the morning, just before lunch, and just before closing—or as often as voicemail is checked. As e-mail becomes a mainstay of office practice, turn-around time should be equal to or better than that of non-urgent telephone calls. Often, the context of the patient's message will indicate an appropriate turn-around time. A patient who enquires about the results of a routine cervical smear will tolerate a longer messaging interval than one who is experiencing even mild side effects from a medication. Forms-based e-mail provided by e-health Web hosting vendors can be more rapidly dispatched than voicemail intake and reply.
- Firmly establish the fact that e-mail is not to be used for urgent communications.
- Indicate escalation instructions, including phone numbers and emergency precautions, on informed consent forms and in the footer of all automatic and written replies.
- Inform patients about whether your account is private or screened by your staff. Will the office staff or nursing staff triage messages, or will mail addressed to your private account be read exclusively by you?
- Establish whether the patient may send you e-mail with express instructions to omit certain parts from the chart. If the patient is allowed to

censor messages from his or her permanent record, can you legally keep an unexpurgated copy in your private files?

- Especially if other clinic staff will be processing e-mail from your patients, establish the extent of action you will permit over e-mail—prescription refills, medical advice, test results.
- Establish actions or content you will not permit in e-mail, such as HIV/AIDS, sexually transmitted diseases, sexual dysfunction, mental illness, worker's compensation, domestic violence.
- E-mail exchanges constitute a form of progress note. Until a fully integrated electronic medical record affords automatic storage, back up, and retrieval of data, e-mail should be printed in full and a copy placed in the patient's records (see Box 3).
- For messages containing important medical advice, and in absence of software with built-in notification features, instruct the patient to acknowledge messages by sending a brief reply. When such acknowledgment is expected, the printed copy should await this final volley.
- Never assume that the patient has received important instructions. When in doubt, as when acknowledgment of receipt is not forthcoming, you must escalate communication to telephone contact.
- Include a footer (signature file) that invites the patient to escalate communication to a phone call or surgery visit, should they feel e-mail to be insufficient, and give the appropriate contact information. You may need to wield a firm hand in discouraging the use of e-mail as a substitute for clinical examination.
- Use automated out-of-the-office replies on any e-mail account which will not be serviced by staff or covering doctors during an absence which exceeds your established e-mail response time. Such messages should include your estimated date of return and instructions for whom to contact for immediate assistance.

Box 3 Keeping copies of electronic correspondence

The following steps result in efficient archiving:

1. Configure your e-mail software to insert the full text of the patient's query in your e-mail reply.
2. Copy the reply to yourself.
3. When the Internet delivers your copy, which now includes both the original message and your reply, print it and file it in the chart. Be sure the printer is not in an area where other patients can see the printouts.

- Maintain a list of patients who communicate with you electronically in the address book feature of your e-mail software. If it becomes necessary to notify correspondents of an impending shutdown for network maintenance, recent mail blackouts, new clinic services, or change of address, you will have a ready-made mailing list (p. 27). However, never use group addressing, where those in the group see each other's names, to send mail to patients. The fact that a person sees a particular healthcare provider is confidential information. Additionally, patients have become indignant over inclusion on lists such as the age-revealing list of women who are due for mammograms. Web-based mailing list servers are useful for group mailings to list members that are not identified to each other.
- Be aware that the impersonal nature and ambiguity of e-mail often results in a real or imagined exaggeration of animosity toward the recipient. Sick, anxious, or angry patients might indeed express stronger sentiments than in a face-to-face encounter or in a voice message. Written policies should specifically prohibit abusive, obscene, or libellous e-mail.
- Be prepared to encounter patients who are sophisticated Internet users, aware of its privacy limitations, who nevertheless initiate unencrypted e-mail discussions of a surprisingly intimate medical nature. If you are uncomfortable replying to e-mail for any reason, do not hesitate to escalate to a phone call or a visit.

Administrative and medico-legal guidelines

Aspects of electronic messaging of particular interest to risk management and legal departments concern data security and liability for advice. The most wary approach is to require patients to sign printed guidelines—a type of informed consent—at the time an electronic relationship is established. In addition to the points in the above communications guidelines, electronic messaging agreements should include:

- Policies and procedures established under the communication guidelines described above.
- An explanation of the general nature of your level of security. Are you using an intranet (p. 15) with a firewall (p. 132)? Are you or is the institution directly connected to the Internet or do you use an Internet service provider who conceivably monitors transmissions? Are you using encryption software (p. 132)? Do you use a Web hosting company that provides secure messaging?

- A clause that allows the patient to 'opt out' of the use of encryption if he or she does not wish to contend with the extra processing required and if there are no laws that require encryption.
- Indemnification for technical failures beyond the control of the health-care providers.

Additionally, you should:

- Avoid leaving open e-mail on your computer screen. If your computer is in the same room as other patients, be sure to use a password-activated screen saver so that patient files are not visible to other patients, especially if you are called out of the room.
- Never forward the patient's message or send patient-identifiable information to a third party without the express permission of the patient.
- Never use a patient's e-mail address in clinic marketing schemes nor supply such addresses to third parties for advertising or any other use.
- As with other parts of the medical record, do not take patient-identifiable e-mail out of the office or surgery. If you answer e-mail from home you must take special precautions to prevent other household members from intercepting messages from patients. Do not share e-mail accounts or passwords with friends, family, or non-medical co-workers. If you communicate with patients, you should have your own account for professional use. Make sure that e-mail processed off-site on home systems or via hand-held devices, for example, is subsequently printed in the office and included in the medical record.
- As soon as practicable, establish a means of secure communication using one of the secure options shown in Fig. 1 (p. 63).

Other issues

Mistakes due to poor interface design and lack of fail-safe mechanisms are particularly troublesome in medical communications. Mistakes have happened that have compromised patient privacy. Until foolproof, encrypted communications become the norm, it is advisable to make a habit of checking the 'To:' box in your message prior to sending it.

Institutional and workflow considerations for e-mail communication

Some analysts predict that healthcare institutions can save significant amounts on demand management overhead by using online tools. Some health plans, especially those with 'capitated plans', anticipate replacing inappropriate office visits with online support. As commercial vendors increasingly address the need for patient-to-provider (P2P) communication, their products should be evaluated for how well they comply with these and other standard sets of guidelines. P2P communication is similar to a medical procedure for which there will emerge best practices.

Institutional policies will need to be developed to address communication and medico-legal guidelines. Questions that must be answered include the following:

- How will you initially establish an e-mail relationship? Is informed consent required?
- Who will triage e-mail and what is to be the response time?
- Who will print messages and place them in the patient's chart?
- Will each provider have his or her own account or will there be categorical accounts for all billing questions, medical questions, and scheduling questions?
- Should all patients be given the provider's e-mail address or can the provider give it out on a selective basis?
- How is e-mail cleared from the server? Does it stay on your local machine and/or on your mail server? How are both repositories archived and cleared?
- Will the patient be given a choice as to what appears from his or her e-mail message in the chart? Do you wish to give the option for 'private' sections of the message that may not be placed in the chart? If you opt not to put all parts into the chart, do you wish to establish a secure repository, either electronic or paper-based, to recall the text of the original message for your own purposes? Or do you want the transaction to be more like a phone call where the conversation is relegated to second-hand progress notes?
- Will encryption systems be required? If so, what kind? Will patients be given the encryption software by the clinic?
- Should clinics provide patients with e-mail accounts on the institutional server?
- What, if any, should be the fee schedule for answering e-mail in lieu of phone calls? In lieu of office visits?

Eventually e-mail storage and retrieval must be integrated within a comprehensive electronic medical record (EMR). World Wide Web-based EMRs (see Chapter 3.2) over secure internal Internet sites (i.e. 'intranets',

p. 15) are a likely model for the future. E-mail is not a substitute for face-to-face clinical evaluation. When in doubt, encourage the patient to make a personal appearance.

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2.3 Communicating in groups

Trisha Greenhalgh

Doctors are increasingly working in groups or teams—both within their own organization (the GP practice, the hospital firm, or the tutorial group) and beyond it (the Primary Care Trust, the learning set, the research collaboration, the special interest group, etc.). An increasing amount of such work now occurs online. Much has already been written about the sociology and psychology of working in groups [1] and there is an emerging research agenda considering how to apply the established principles of effective group work in a virtual environment.

What is a group?

A more detailed definition is given elsewhere [1], but in essence members of a group share:

- A common identity.
- A common purpose or task.
- A shared frame of reference.
- A characteristic pattern of interaction, described further below.

Many of the online exchanges that occur via e-mail and bulletin boards (online forums) are no more than a series of loosely linked messages and do not strictly constitute group interaction. Whilst such encounters have an interesting psychological dimension [2,3] they do not fulfil the defining criteria of a group listed above and will not be considered further here.

Most groups tend to develop through four main stages [4]:

- Forming (putting the group together and getting to know each other).
- Norming (defining the purpose of the group and setting ground rules for individual and group behaviour).
- Storming (generating and managing dissent and conflict).
- Performing (working effectively together to meet the agreed objectives).

When a group is not working well (i.e. when it is not delivering on its agreed or assigned task), it may be blocked at one of these stages of development. Alternatively, individuals may be behaving dysfunctionally. For example:

Contributing too much, including:

- The dominator (who talks at length and ignores boredom cues from others).
- The enthusiast (who is often knowledgeable, extrovert, and helpful but insensitive to the needs of silent members and the general pace of discussion).

Hardly contributing at all, including:

- The timid member (who is motivated to contribute but remains silent through shyness or lack of self-confidence).
- The passive aggressor (who has destructive motives and seeks to manipulate the mood of the group through silence or failure to acknowledge the contributions of others).

Contributing inappropriately, including:

- The digressor (who fails to distinguish an illuminating tangent from time-wasting irrelevancies).
- The pedant (who dwells on semantics or details).
- The joker (who uses humour as a conscious or subconscious wrecking tactic, with frivolous, stupid, sexist, or racist comments that undermine group cohesion and distract it from its objective).
- The rank-puller (whose contributions seek to challenge or subvert the designated leader).

Facilitating (usually known as 'moderating' in an online context) a group is very different from being the 'boss' or addressing the task alone. In addition to important administrative functions (such as reminding people where course reading is to be found, or posting copies of past e-mails [5]), the facilitator has two main roles:

Task role (i.e. ensuring that the group completes its task). For example, by:

- Focusing members on the agreed topic.
- Clarifying and elaborating contributions of group members.
- Summarizing work done so far.
- Questioning the direction and depth of discussion.

Group role (i.e. establishing and maintaining effective group functioning). For example, by:

- Promoting a climate that is open, supportive, and trusting.
- Gatekeeping (i.e. ensuring that members with a contribution to make have the opportunity to do so).
- Relieving tension (for example, through humour).
- Setting standards by encouraging members to establish and follow ground rules.
- Identifying and managing dysfunctional behaviours (see above) that may interfere with the group process.

Features of online groups

Whilst the basic principles of effective group work apply equally to an online environment, there are six areas in which the online group differs crucially from its face-to-face equivalent. These are considered below.

Dependence on technology

The online group has three main methods of interaction:

- Simple interpersonal e-mail exchange (p. 25).
- E-mail exchange via a mailing list (p. 27) or newsgroup (p. 29).
- Online forum messaging using specialist software, typically Web-based.

Studies of online educational courses suggest that the amount of training needed to become comfortable with specialized software packages may be considerably greater than the organizers of the project initially assumed [6, 7]. In this author's experience, setting up a mailing list or newsgroup and informing prospective members of its existence is generally an inadequate stimulus for active participation in the online group—even when members are motivated to contribute (and especially when they are not!).

Absence of non-verbal cues

The culture of online communication is very different from face-to-face interaction [8]. In a conventional face-to-face group, participants essentially use the same communication skills they use in everyday life: facial expressions such as smiling or frowning, changes in verbal emphasis or tone of voice, hand gestures, and the subtle use of eye contact. Although many aspects of face-to-face group work (such as punctuality, confidentiality, respect for differing views, and so on) must be learnt and agreed as ground rules, the basic currency of interpersonal communication has generally been learnt in early childhood.

In contrast, the participants in an online group must learn a whole set of new cues and techniques (netiquette) to support effective communication. They cannot see from body language if their fellow participants are bored, hostile, distracted, or inattentive. Neither tears nor smiles come down the telephone line, and silence online can have all sorts of meanings! It would appear that the virtual group can be an emotionally barren and socially alien environment compared to the cosiness of face-to-face interaction—at least until the participant is familiar with the new culture. Table 1 suggests some virtual equivalents of traditional nonverbal cues.

One very practical implication of the absence of non-verbal cues in group work is size. In general, face-to-face groups usually have between three and eight members. Online groups are different: indeed, the size of the group is sometimes impossible to determine if membership is open and 'lurkers' (participants who read but don't post messages) are not readily identifiable. What matters more is the size of the active and visible group, since research suggests that whilst the lurker may gain considerably from following the contributions of others, he or she has little impact on the group dynamics. Ideal sizes for different types of online group have been suggested [5]; groups of 5–20 participants work fairly well for most purposes.

Geographical and cultural dispersal

An online group can potentially have members anywhere in the world. This makes the group open to a range of expertise, and enhances the potential for bringing together people from very different backgrounds. Members of an online group may have far fewer shared assumptions and values, and they may even speak different languages. The additional burden that this creates for both members and facilitator are often overlooked in the face of the more immediate and obvious challenges of computer based interaction.

The lack of visual and other non-verbal cues may have advantages as well as disadvantages. It is not immediately obvious, for example, that a person commenting on an e-mail message is a doctor or nurse, consultant or registrar, UK or foreign-trained, or even if they are white or black, physically disfigured, or speaking with an accent that betrays a particular social class.

Table 1 Suggestions for virtual substitutes for non-verbal cues in group work

Traditional non-verbal cue	Usual interpretation of this behaviour	Indicator of similar emotional response in virtual group
Looking attentive, smiling, leaning forward, making eye contact	Attention, support, warmth, empathy	Explicit postings; e.g. 'Well said' or 'Yes, I agree', which have been termed 'say-writing'[1]; 'Emoticons';[2] e.g. ^5 for 'high five', (((name))) for 'hug'—tedious if overused
'Secret' body language between two members; e.g. eye contact, winking, smiling	Empathy, support (especially if aggression or negative input from a third party)	Private e-mail message sent separately from any group list or forum
Laughter or other emotional 'releases'	Relief of tension	Verbal humour or emoticons; e.g. ;-) indicates wink :-0 indicates surprise :-X indicates my lips are sealed
Sitting outside the circle of group members; using 'closed' body language	Withdrawal from the group	Reduction in frequency of postings from that member, heavy use of private e-mail to members rather than 'sharing' messages with the group as a whole
Yawning	Boredom (especially if displayed by several members)	Few or no responses to this thread from other group members, or emoticon; e.g. |-0 indicates yawn :-(indicates frown/sad
Aggressive gestures accompanying speech; e.g. standing up, table thumping	Attempt to convey strong emotion such as anger	Use of capital letters; e.g. 'DON'T FLY OFF THE HANDLE—I WAS ONLY TRYING TO HELP' or emoticon; e.g. :-> indicates shouting
Emphatic gestures accompanying speech; e.g. hand waving, drawing on pipe	Drawing attention to key words or phrases	Use of asterisks around the key words; e.g. 'I think we should discuss the *sexual* implications of this case'

[1] Mason R. Written interactions. In Mason R (ed.). *Computer conferencing: the last word*. Victoria, British Columbia: Beech Holme; 1993.

[2] For a list of emoticons see http://enternet.com.au/techno/emoticons.html

Timing of interaction

There are two main ways in which members of the group can interact online:

- Synchronous (real time) interaction, in which everyone logs on at the same time. This method, usually referred to as 'chat', is commonly employed for recreational purposes but is relatively little used in official courses.
- Asynchronous interaction, in which members of the group each log on at their own convenience, check for new contributions from other group members, and post their own messages for others to see (see Fig. 1).

Asynchronous interaction has a number of advantages. Firstly, group members are freed of temporal as well as geographical constraints. Members

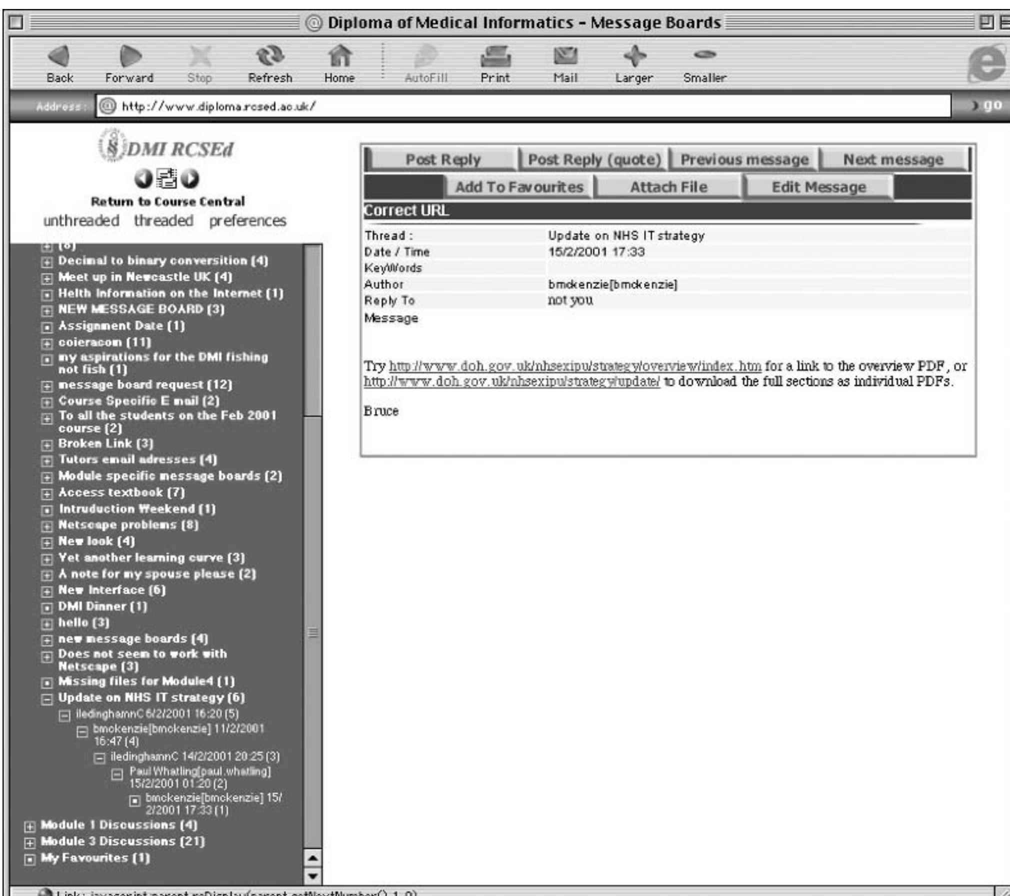

Fig. 1 An example of an asynchronous Web-based bulletin board.

with unpredictable workloads and or competing commitments can do their 'group work' at a time that other members would find distinctly antisocial.

Secondly, and perhaps more significantly, the virtual group process offers the opportunity for reflection. The less able or less confident member can draft a response and reflect on it before sending it to the rest of the group. A person who feels they 'never get a word in edgeways' can create additional opportunities to participate by logging on more frequently. Conversely, someone with a tendency to make hasty comments that they later regret can construct a response but delay sending until the following day, when a more measured contribution may have occurred to him or her.

Finally, because bulletin board contributions are often 'threaded' (i.e. responses can be automatically linked to the comment to which they pertain, rather than to the last comment made by any group member), asynchronous communication allows discussion to proceed in a non-linear way. The use of threads is one aspect of online group work that participants must learn and adhere to, since inadvertently posting a response to one message as a reply to a different message will quickly cause confusion in the group.

Facility for private communication

How many times, when participating in a face-to-face group, have you tried to convey a message to another member—either to offer empathy, show support, or suggest that they shut up and let someone else say something? In the face-to-face situation there is little you can do until the group session has finished, when the moment for your contribution may have passed. Furthermore your attempted one-to-one with another group member may be interpreted as excluding by the other members.

In contrast, in the online group the use of private e-mail in parallel with the group discussion is rarely even noticed, let alone resented, by the group as a whole. The weaker members can be supported, and the dysfunctional ones confronted, without the group even being aware that this is occurring. Indeed, private e-mail can be used explicitly as a tool for managing the group process. For example, the tutor might say 'I can see that Fred and Joan are still working on their dispute about how many different types of porphyria there are. Why don't you two discuss this privately and give us a 50-word summary in a few days' time?'

The downside of private e-mail is that an insensitive or manipulative group member might use this technique to pull rank on (and even bully) other members. The premeditated luring of naïve group members into private encounters has an even more sinister aspect. The paedophile who lurks in Internet chat rooms in search of children, the anti-Semite who adopts a pseudonym to join a Jewish support group, or the male aggressor intent on 'virtual rape', are examples of undesirable personality types that psychologists have begun to describe and explore [3].

Recording the group process

The electronic medium automatically creates a detailed, permanent, and potentially indexable record of the entire group process. Individual group members may look back over contributions, and remind their fellow participants of messages sent several days or weeks previously. If specialized software is used, contributions may even be numbered, making cross-referencing very easy (e.g. 'As I said in message 3245, …'). Tutors may call attention to particular sequences of communication to illustrate lessons about group process (which may have gone unnoticed at the time as participants focused on content). Whereas video-recording of a face-to-face group fundamentally changes the interaction (because people 'play to camera'), the recording of the virtual group process generally goes unnoticed, potentially creating a rich archive for researchers!

Suggestions for effective online group work

Address issues of technology and IT competence. If you are seeking to pull together an online group:

- Use technology that everyone possesses and is familiar with (e.g. simple e-mail).
- Do not rely on a local server that might crash or produce technical glitches.
- Encourage each group member to test the water at an early stage. For example, to post an initial message and respond to a posting by someone else.
- Recognize that some individuals acquire essential IT skills more slowly than others, and offer a confidential and blame-free remedial training service for the less confident members.
- Accept that effective group interaction will not happen until a minimum level of technical competence is reached.

Encourage and support the use of textual substitutes for non-verbal cues (see Table 1). As discussed above, the lack of non-verbal cues can make online group work dry and unengaging.

Encourage sensitivity to the wide range of backgrounds and contexts from which group members may be drawn. To make the best use of the culturally dispersed group:

- Include as a ground rule the avoidance of parochial language, idioms, acronyms, and jargon.
- Ensure that the tutor or facilitator shows empathy with those from other countries or cultures when undertaking the clarifying role.
- If a contribution draws heavily on the context of experience, first ask the contributor to explain this context. Then, explicitly invite those from other backgrounds to contribute similar or contrasting examples. In this way, the cultural and contextual differences within the group can be explicitly utilized to enhance learning.

Promote effective use of asynchronicity. Encourage the group members to:

- Log on frequently to view new contributions, but not to respond to each posting as soon as they see it.
- Send a draft response to the tutor or another member for review prior to posting if they are under-confident.
- Edit their contributions before posting if they tend to 'talk too much' or digress.

Promote effective use of private e-mail. To ensure that private e-mail supports rather than undermines the online group process:

- When setting ground rules, prompt the group to establish rules for private e-mail as well (making sure you obey them yourself!).
- If using dedicated software, clarify to members whether the course director can gain access to private exchanges.
- Encourage any member who feels uncomfortable about a private message to share it with the group or send it in confidence to the facilitator or tutor.

Review, and reflect on, the written record of the group process. To make best use of the written record:

- Include a review of specific (numbered) sequences of interaction as part of the evaluation of the group process by the group members.
- Archive and index the record.

Conclusion

Doctors should be relieved that technology has freed the group and the team from the geographical and time constraints of face-to-face meetings.

This chapter has argued that the principles of effective group work are generally transferable to the online environment, but that poor facilitation (moderating) and dysfunctional behaviour from members are also a risk in the virtual group.

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3 Using the Internet for clinical care

iNFOpulse

Accessing evidence-based practice

- Evidence-based practice (EBP) involves the integration of high-quality research evidence with individual clinical expertise and the explicit, conscientious, and judicious consideration of the best available evidence in making healthcare decisions.
- EBP resources on the Web include articles underpinning the development of the EBP paradigm; information and products from EBP organizations and networks; critical appraisal guides/checklists; clinical calculators; and materials to answer your clinical questions—databases, structured abstracts, systematic reviews, critically appraised articles and topics, and health technology assessment reports.
- Limitations of the Internet for EBP include the lack of editorial control and peer review; the lack of regular update mechanisms; sources are hard to identify, navigate and verify; resource development is patchy and sporadic; and information is often poorly organized and of highly variable quality and relevance.
- When searching for clinical evidence focus your question using four elements: patient or problem, intervention, the comparison, and the outcomes (PICO); use resources that filter results via methodological terms; select acknowledged EBP sources; and use material that has undergone peer review.

Clinical information and decision-support systems

- The rapid increase in both quantity and importance of clinical data requires new methods for data management.
- The Web provides flexible and easily configured tools to manage clinical data.
- Networked medical record systems can improve clinical communication between healthcare workers and with patients.
- Data entry is a key barrier to the deployment of Web-based (and other) electronic medical record systems.
- Decision-support systems apply medical knowledge to patient-specific data.
- The best-validated decision-support systems are rules to alert or remind physicians of important but focused clinical problems such as drug allergies.

continued

Telemedicine consultations

- The Internet has been used successfully for monitoring patients at home; e.g. those with diabetes or asthma.
- Both e-mail and the Web have been used for image transmission; e.g. to allow assessment of extremity injuries.
- Real-time teleconsulting uses more expensive equipment than asynchronous techniques, such as e-mail. The latter are cheaper and more convenient than real-time teleconsulting although the diagnostic accuracy of e-mail-based teleconsulting may not be as high.
- Teleradiology is the most mature telemedicine application; the business case is clear, especially for small hospitals.
- Teleconsulting carries medico-legal risks, although probably not significantly worse than in conventional practice, so long as doctors behave in a prudent manner.

Security, privacy, and confidentiality issues

- Assume everybody wants your data—they do!
- Learn about the risks *before* you connect.
- Manage your own connection, and educate yourself and your staff.
- Remember the law and the ethical duty of confidentiality—you are responsible for data safety.
- Employ virus protection.
- If it moves, encrypt it. If it's stationary, protect it.

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3.1 Accessing evidence-based practice

Andrew Booth

Evidence-based medicine (EBM), with its related evidence-based practice (EBP), *seems* eminently suited to access via the Internet [1,2]. EBM aims:

- To facilitate the integration of high-quality research evidence with individual clinical expertise.
- To encourage the 'explicit, conscientious and judicious consideration of the best available evidence in making health care decisions' [3].
- To support appropriate patient care.

EBM on the Internet

Numerous resources attest to the growth of EBM on the Web [4]. EBM organizations and networks co-ordinate and disseminate their activities via Web-based resources. Key documents, practical tools and checklists are accessible to a growing international community. Materials to answer your clinical questions—databases, structured abstracts, systematic reviews, critically appraised articles and topics, and the products of health technology agencies—are increasingly available in hypertext, or as downloadable Microsoft Word or Adobe portable document format (PDF) files.

The Internet, however, is not a natural system of choice for supporting clinical decisions [5] as:

- it has no editorial control or peer review processes [1];
- it has no regular update mechanisms;
- sources are hard to identify, navigate and verify;
- development is patchy and sporadic.

As Jadad *et al*. observe 'Internet users, regardless of their role, background or knowledge, can experience confusion and anxiety because of the virtually unlimited amount of information available, information that is often poorly organized and of highly variable quality and relevance' [6]. The Internet occupies its role in supporting evidence-based healthcare (EBHC) largely by default. Textbooks are outdated, even before they are published, and slow to be revised [7], the journal literature is fragmented, libraries are unavailable for the larger part of the 24-hour clinical working day [8], and commercial databases require subscriptions and specialist information retrieval skills. Yet the Internet has changed 'how we access information and what we can view' [9] and has stimulated development of the UK's National electronic Library for Health (NeLH) [10].

Learning about EBP

To find out about EBP you can access documentation on its rationale, origins, methods, and resources via the Internet [11]. EBM was 'launched' in 1992 in the *Journal of the American Medical Association* as a new paradigm for teaching the practice of medicine [12]. These ideas were expanded by the team at McMaster University in *The medical literature as a resource for evidence based care*. Following unexpected criticism from the UK medical profession David Sackett and his supporters redefined EBM [13] to address a number of misunderstandings.

A new approach to teaching the practice of medicine:
http://www.cche.net/usersguides/ebm.asp

The medical literature as a resource for evidence-based care:
http://hiru.mcmaster.ca/hiru/medline/asis-pap.htm

Evidence-based medicine: what it is and what it isn't:
http://cebm.jr2.ox.ac.uk/ebmisisnt.html

Supporting the methods of EBP

In addition to documenting the origins of EBM, the Internet is a rich source of material to support the methods of EBP. This material includes resource lists, documents, interactive tools, and critical appraisal checklists.

Resource lists

To comprehend the variety of EBP resources your best starting point is a comprehensive resource guide. The author's own *Netting the evidence* [14] is used by the Cochrane Library for this purpose (see Fig. 1):

http://www.nettingtheevidence.org.uk/

Other well-regarded resource lists are those of the University of Hertfordshire and the New York Academy of Medicine.

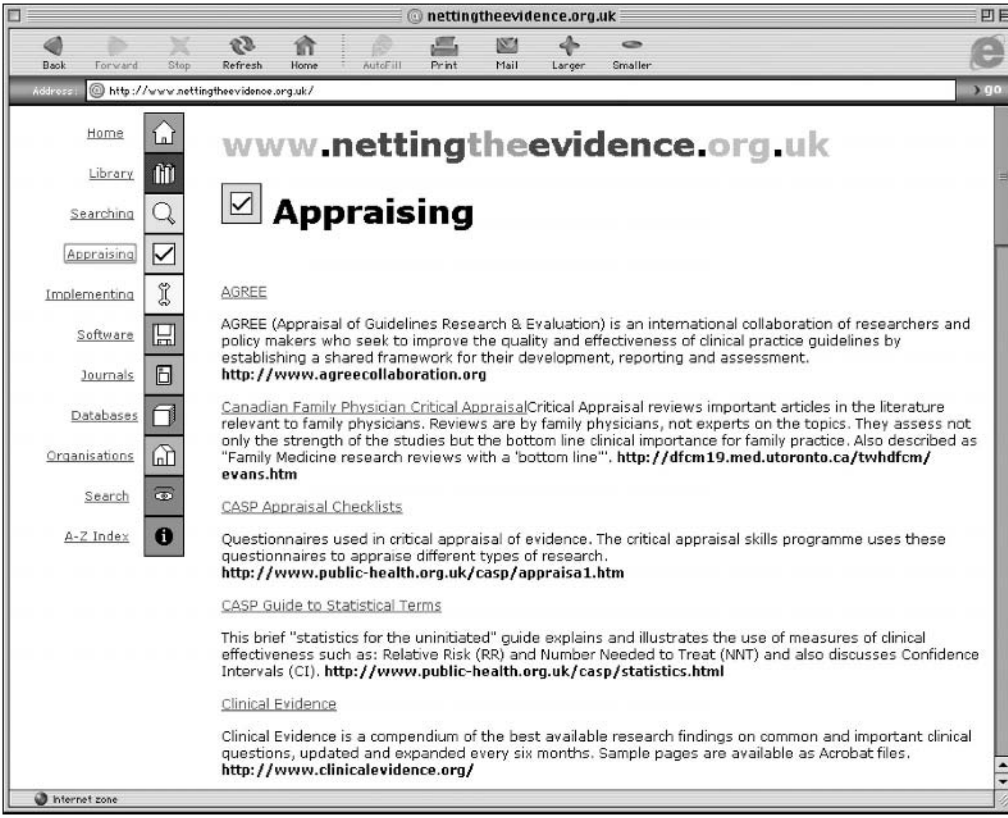

Fig. 1 *Netting the evidence* is a comprehensive guide to EBP resources on the Internet.

University of Hertfordshire:

http://www.herts.ac.uk/lis/subjects/health/ebm.htm

New York Academy of Medicine:

http://www.ebmny.org/

Documents

You can access full-text articles and reports from the above resource lists. Essential readings are collected at the ScHARR site and by GIMBE (Gruppo Italiano per la Medicina Basata sulle Evidenze).

ScHARR:

http://www.shef.ac.uk/~scharr/ir/core.html

GIMBE:

http://www.gimbe.org/

Foremost among these are the *Users' guides to evidence-based practice* devised by the Evidence Based Medicine Working Group to assist you in appraising and interpreting different types of primary or secondary articles:

http://www.cche.net/usersguides/

A complete list of bibliographic details for the *Users' guides to evidence-based practice* is found at:

http://www.shef.ac.uk/~scharr/ir/userg.html

Tools

Evidence-based medicine originated as 'clinical epidemiology' [15] and continues to emphasize tools that calculate clinically meaningful measures such as 'numbers needed to treat' [16]. You can download Web-based tools with formulas for calculating results from published research or use them interactively via the Web. For example, the Centre for Evidence Based Medicine (University of Oxford) provides a range of calculators while CHE.net links various tools to your specific question type.

University of Oxford:
http://cebm.jr2.ox.ac.uk/docs/toolbox.html

CHE.net:
http://www.cche.net/usersguides/

Checklists

Checklists are invaluable prompts to asking the right questions of research articles. Optimally these are based on the *Journal of the American Medical Association* Users' Guides that can be accessed online from CHE.net. Look particularly at the versions of the guides adapted for the NHS by the Critical Appraisal Skills Programme (CASP). Parallel activities in other countries are demonstrated by CASP International:

Critical Appraisal Skills Programme:
http://www.phru.org.uk/~casp/

CASP International:
http://www.caspinternational.org.uk/

Improving access to quality information

The synergy of evidence-based health information with technological advances is best illustrated with reference to two specific initiatives, the

Cochrane Collaboration and the National electronic Library for Health (NeLH). Respectively, these epitomize the production end and the consumption end of the so-called 'evidence chain'.

The Cochrane Collaboration

Coverage of EBP would be incomplete without acknowledgement of the substantial contribution of the Cochrane Collaboration. This is an international network committed to preparing, maintaining, and disseminating systematic reviews of the effects of healthcare [17]. It was set up to evaluate the available evidence from randomized controlled trials. Details of its activities and entities are found on any of the Cochrane mirror sites, for example:

US Cochrane mirror:
http://www.cochrane.org/

UK Cochrane mirror:
http://www.update-software.com/ccweb/

The Cochrane Library is the main product of the Cochrane Collaboration:
http://www.update-software.com/clibhome/clib.htm

You can use the Cochrane Library to access high-quality evidence designed to inform your healthcare decision-making. It is published quarterly over the Internet and includes:

- the Cochrane Database of Systematic Reviews (CDSR)
- the Database of Abstracts of Reviews of Effectiveness (DARE)
- the Cochrane Controlled Trials Register
- other sources of information on evidence-based healthcare.

To learn how to use the Cochrane Library you can access training materials prepared by the NHS Centre for Reviews and Dissemination (CRD) at the University of York together with teaching materials that explain how to interpret the findings of systematic reviews:
http://www.york.ac.uk/inst/crd/cochlib.htm

Although the full Cochrane Library is available only by subscription, abstracts of the systematic reviews are available without charge from:
http://www.update-software.com/abstracts/mainindex.htm

The NeLH

The UK's NeLH aspires to providing high-quality filtered and peer-reviewed evidence-based products to clinicians [18]. It aims to provide a single gateway to free Internet resources and selected commercial products such as the *Cochrane Library*, *Clinical Evidence* and the electronic *British National Formulary*. Specialist gateways—virtual branch libraries (VBLs)—aim to provide access by disease area (e.g. coronary heart dis-ease or diabetes), or to a specific client group (e.g. health managers or primary care).

NeLH:
http://www.nelh.nhs.uk/

Using online evidence to answer clinical questions

As a practising physician you will want to answer clinical questions from the Web rather than merely learn the methods of EBP [19]. A real-world scenario illustrating the potential for appropriate use of the Internet is provided in Box 1.

Box 1 Scenario

A middle-aged otherwise healthy businessman presents to your surgery with flu symptoms. He has heard of the new anti-viral drugs for influenza and will try anything if it means he can attend his annual sales meeting. While he answers an urgent call on his mobile phone you conduct an Internet search for evidence on influenza and zanamivir.

Defining the question

In managing the scenario outlined in Box 1 your first step is to focus your question using the 'PICO' anatomy [20,21]. This involves deconstructing your clinical query into four elements: the Patient or Problem, the Intervention of interest, the Comparison intervention, and the intended Outcomes [22]. This will make your search more precise [23]. In this example the elements are:

Patient	Middle-aged male with influenza
Intervention	Zanamivir (Relenza)
Comparison	Other treatments or no treatment
Outcomes	Relief from flu symptoms, reduction in duration of illness, etc.

Identifying appropriate resources

Resources likely to provide reliable answers to your clinical questions will possess three characteristics:

1. They filter results using methodological terms. You either qualify your subject query with terms that indicate higher-quality articles or else the database producer only includes materials identified in this way.
2. They select acknowledged EBM sources.
3. In the absence of 1 and 2, they only use material that has undergone peer review, either prior to publication or subsequently when added to a resource.

We have selected ten resources with one or more of these characteristics for special mention (see Table 1). However, you can apply these criteria

Table 1 Suggested 'top ten' resources for locating evidence-based materials

Resource	Type	Filters	EBM sources	Peer review
Turning Research Into Practice (TRIP) Database: http://www.tripdatabase.com/	Gateway	✓	✓	✓
PubMed MEDLINE Clinical Queries Interface: http://www4.ncbi.nlm.nih.gov/PubMed/clinical.html	Database	✓		✓
SUMSearch: http://sumsearch.uthscsa.edu/	Gateway	✓	✓	✓
Drs Desk: http://www.nelh-pc.nhs.uk/	Gateway		✓	
Database of Abstracts of Reviews of Effectiveness: http://nhscrd.york.ac.uk/	Database	✓	✓	✓
NHS Economic Evaluations Database: http://nhscrd.york.ac.uk/	Database	✓		✓
National Guidelines Clearinghouse: http://www.guidelines.gov/	Database		✓	✓
MDChoice: http://www.mdchoice.com/index.asp	Gateway			✓
CliniWeb: http://www.ohsu.edu/cliniweb	Gateway			✓
AltaVista using filters: http://www.altavista.com/	Search engine	✓		

Box 2 Description of suggested 'top ten' EBM resources

1 **Turning Research Into Practice (TRIP) Database.** A meta-resource (i.e. providing simultaneous access to many high-quality evidence sources) comprising over 20 000 individual links. An excellent one-stop shop. See Fig. 2.

2 **PubMed MEDLINE Clinical Queries Interface.** This interface to MEDLINE (Chapter 6.1) restricts subject searches to high-quality articles by looking for methodological terms (e.g. 'randomized controlled trial') in the title, abstract or index (MeSH) terms [24].

3 **SUMSearch.** Developed by the Society for General Internal Medicine, SUMSearch runs a subject query against high-quality resources such as filtered MEDLINE, DARE and the National Guideline Clearinghouse [25]. It provides references to questions about diagnosis, aetiology, prognosis, and therapy (plus other topics) using quality filters developed at McMaster University [26].

4 **Drs Desk.** Provides access to a selection of high-quality EBP resources [27], forming part of the NeLH Primary Care interface.

5 **Database of Abstracts of Reviews of Effectiveness.** DARE is produced by the NHS Centre for Reviews and Dissemination (CRD) at the University of York and contains structured abstracts summarizing the content and methods of systematic reviews. The best systematic reviews are identified by regularly searching major healthcare databases, by hand-searching key journals, and by scanning grey literature (i.e. elusive literature issued through non-commercial channels).

6 **NHS Economic Evaluations Database.** Also produced by CRD, contains detailed structured abstracts of economic evaluations. Records include a summary, an assessment of study quality and practical implications for the NHS. Costing studies, methodological articles, or reviews have basic bibliographical details only.

7 **The National Guideline Clearinghouse.** This US resource allows comparisons between structured evaluations of two or more guidelines and has links to full-text where available.

8 **MDChoice.** A commercial search facility using the Unified Medical Language System (UMLS) from the National Library of Medicine to index online medical sites. Each site is peer-reviewed by clinicians.

9 **CliniWeb International.** A searchable and browseable index organized according to Medical Subject Heading (MeSH) disease and anatomy classifications. It indexes 10 000 URLs containing information for healthcare education or practice.

10 **Alta Vista using filters.** General search engines are far less discriminating than the specialized resources mentioned above. An approach, still in its infancy but yielding useful empirical results, is to combine terms from Patient and Intervention concepts using the Boolean operator 'AND' and then to filter retrieved results by adding 'AND random* control* trial*' (for therapy questions) to the search statement (e.g. aspirin AND 'myocardial infarction' AND 'random* control* trial*').

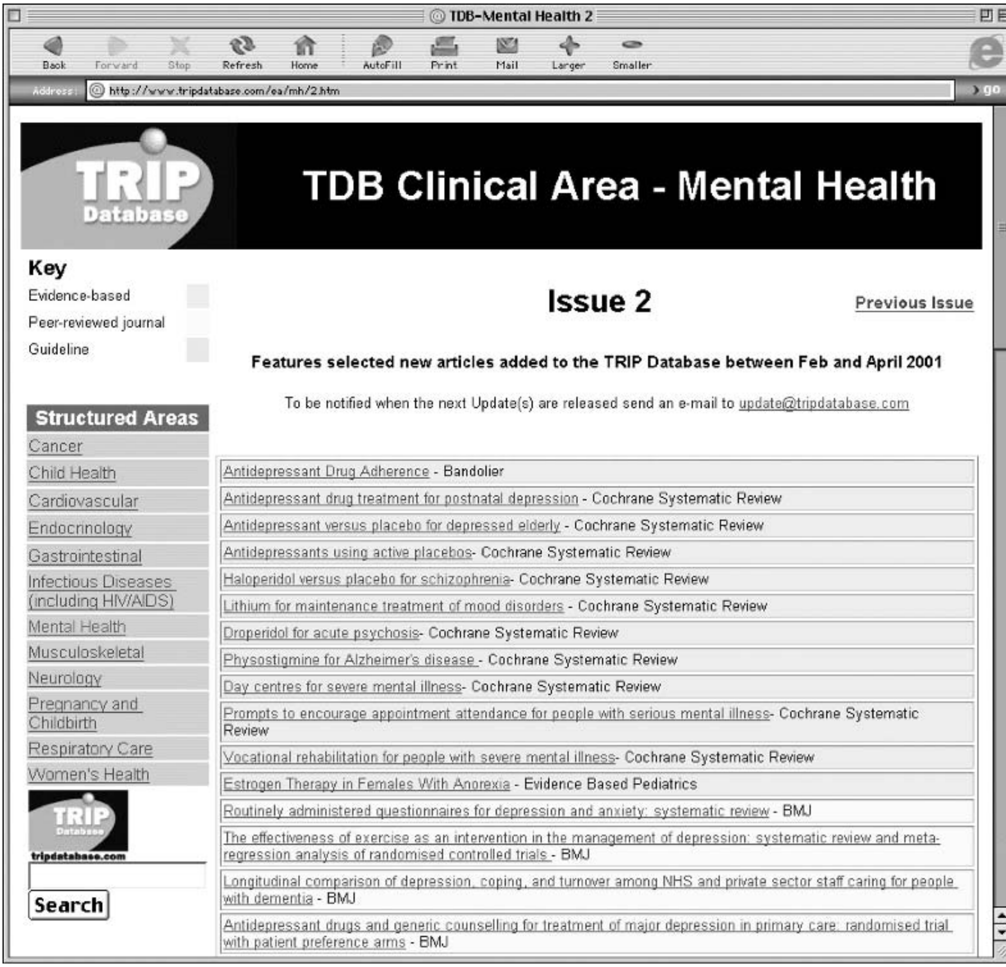

Fig. 2 The *Turning Research Into Practice* (TRIP) database is a meta-resource, providing simultaneous access to many high-quality evidence sources.

to new resources as they appear. Short descriptions of the selected resources are given in Box 2.

Resolving the scenario

Searching the ten resources described in Box 2 retrieved a variety of materials that might be useful in resolving the clinical question posed above (see Table 2).The materials identified included such evidence-based products as:

- critically appraised articles;
- online journal clubs;

Table 2 Evidence yield from ten resources

Evidence	Sources
Digests from ACP Journal Club, Bandolier, MD Digests, POEMS, Evidence Based Pediatrics	TRIP, Drs Desk
Guidance from the National Institute of Clinical Excellence (NICE)	TRIP, Drs Desk
Health technology assessment report	TRIP
Full-text from peer-reviewed journals *NEJM*, *BMJ*, and *Ann. Intern. Med.*	TRIP, SUMSearch, PubMed
4 Systematic review references	TRIP, SUMSearch, DARE, PubMed
1 Cochrane abstract	Drs Desk, DARE, SUMSearch, TRIP
1 Cost effectiveness study	PubMed, SUMSearch, NHS EED
1 Continuing medical education link, 8 peer-reviewed links, and 15 consumer links	MDChoice
112 Web pages mentioning randomized controlled trials	Alta Vista

- critically appraised topics;
- health technology assessment reports.

The examples that follow are not specific to our scenario, but illustrate the range of resources available.

Critically appraised articles

The critically appraised article originated in *ACP Journal Club* in 1991, a supplement to the *Annals of Internal Medicine*. This model has sub-sequently been followed by *Evidence-Based Healthcare*, *Evidence-Based Medicine*, and *Evidence-Based Mental Health*. The Web sites for these journals include either selected abstracts or the tables of contents for recent issues:

ACP Journal Club:
http://www.acpjc.org/

Evidence-Based Health Care:
http://www.harcourt-international.com/journals/ebhc/

Evidence-Based Medicine:
http://www.acponline.org/journals/ebm/pastiss.htm

Evidence-Based Mental Health:
http://www.ebmentalhealth.com/

Online journal clubs

Online journal clubs deliver an evidence-based journal club via the Web. For example, Journal Club on the Web periodically summarizes and critiques articles from the medical literature and collects and posts readers' comments. Family Medicine Research Reviews critically appraises articles aimed at general practitioners for the journal *Canadian Family Physician*:

Journal Club on the Web:
http://www.journalclub.org/

Family Medicine Research Reviews:
http://dfcm19.med.utoronto.ca/twhdfcm/evans.htm

Critically appraised topics

CATmaker is an Internet-based tool, developed at the Centre for Evidence Based Medicine in Oxford, to help clinicians to summarize the evidence. Resultant summaries are known as 'critically appraised topics' or CATs [28]. Sample CATS are found at the sites of the Centre for Evidence Based Medicine (UK) and the University of Rochester (US):

CATmaker:
http://cebm.jr2.ox.ac.uk/docs/catbank.html

Critically Appraised Topics (Centre for Evidence Based Medicine):
http://cebm.jr2.ox.ac.uk/cats/catsearch.html

Critically Appraised Topics (University of Rochester):
http://www.urmc.rochester.edu/medicine/res/CATS/Cathome.html

Health technology assessment reports

Although valuable, Health technology assessment (HTA) reports are uncommonly assimilated by busy doctors. They are generally broad systematic overviews of new health interventions and thus can provide an invaluable state-of-the-art summary of evidence. You can identify these using the HTA Database from NHS CRD. Major agencies include the UK National Co-ordinating Centre for HTA (NCCHTA), and those in New Zealand (NZHTA) and Canada (CCOHTA). Rapid technology appraisals conducted for the National Institute for Clinical Excellence (NICE) also provide useful syntheses. HTA is a burgeoning field, well documented elsewhere in the literature [29,30]:

HTA Database:
http://agatha.york.ac.uk/htahp.htm

UK National Co-ordinating Centre for HTA (NCCHTA):
http://www.hta.nhsweb.nhs.uk/index.htm

New Zealand Health Technology Agency (NZHTA):
http://nzhta.chmeds.ac.nz/

Canadian Co-ordinating Office for Health Technology Assessment (CCOHTA):
http://www.ccohta.ca/

National Institute for Clinical Excellence (NICE):
http://www.nice.org.uk/

Barriers to using the Internet at the point of care

Smith defined requirements for clinical information tools as 'electronic, portable, fast, easy to use, connected to both a large valid database of medical knowledge and the patient record, and a servant of patients as well as doctors' [31]. By such criteria the Internet has a long way to go. Our exemplar search took 56 minutes to conduct—only to identify, let alone appraise the material. It involved 10 different interfaces, a telephone connection and desktop PC, retrieved materials of differing depths and quality, and was divorced from the patient record. Most of the evidence was, however, retrieved within 10 minutes from just three resources.

The impact on patient care

Inaccurate or inappropriate health information can result in inappropriate treatment [32,33] or delays in seeking medical care [34]. Information on the Internet is difficult to verify. Potentially misleading claims for medical products are virtually endemic [35]. Research to date has looked at potential for harm rather than its actuality—either by soliciting advice for a hypothetical patient [36,37] or by rating the quality of sites on a particular topic [38,39].

Conclusion

In 1996 Hersh [9] observed that for the Internet to play an increasingly important role in EBP would require better methods for navigating the Web and focusing on high-quality evidence-based content, and resolution of issues relating to copyright, economics, and peer review. Despite impressive advances made by both the Internet and EBP in the last 5 years these two significant challenges must be overcome if the Internet is to become a 'comprehensive, dependable and indispensable tool for clinical practice' [9].

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3.2 Clinical information and decision support systems

Hamish Fraser

Introduction

Working physicians don't need to be reminded of the vast and growing mountain of data collected on each patient, paralleling the explosion of medical literature. In addition the dramatic improvements in treatments for conditions such as ischaemic heart disease demand speed and consistency in their application. In response to this electronic medical record (EMR) systems have been developed to store, organize, and provide access to this medical data. This task is challenging, but if done well can be a great help in organizing important information, speeding up communication, and helping to prevent omissions or errors. Decision support systems are computerized tools that apply medical knowledge to clinical data to provide advice for diagnosis or treatment decisions. A brief overview of these systems is presented here; for more information consult a general text on medical informatics [1– 3].

The first EMRs were developed in the 1960s in the US, largely to simplify patient billing, but it is the UK that has pioneered the EMR in primary care. Over 95% of practices now use such systems [2] compared to well under 50% in the US. There are a number of benefits to using an EMR (see Box 1) but some of these, such as the ability to support multiple simultaneous users or share data between primary care and specialists, require a networked system. The disadvantages are mainly the time required to learn to use the system and to enter data, and security concerns.

Box 1 Pros and cons of electronic vs. paper records

Paper record	Electronic record
One user at a time	Many users
May be fragmented	Integrated system (you hope)
Poor legibility	Clearly readable
Hard to find data	Structured, searchable
Easily lost	Good backups and availability
Local to site	Accessible at a distance
Hard to compare patient data	Easy data aggregation
Bulky	Very compact storage
Requires physical security	Requires physical security and encryption
Easy to understand and use	Requires training
Quick to add data to	Can be difficult and slow to enter data

Clinical data and the Web

While the Internet has been used to access hospital medical records for over a decade, the technology that 'changed the rules' was the Web. Suddenly it was possible to access text and images about a patient from almost any computer with a modem or network connection. Expanding access to microbiology data and other laboratory data is a good example [4]. Current Web sites typically combine data storage, in a database, with forms and reports displayed as Web pages [5,6]. These database-backed Web sites are best viewed as comprising three layers (see Fig. 1). This flexible design allows the substitution of different databases and a variety of computer systems (e.g. Windows, Macintosh, or Linux) can access the Web pages. Systems of this sort are also quicker to build than previous programs (e.g. DOS or Windows) and require less maintenance. This characteristic allows incremental development; i.e. a basic system can be set up, then expanded to cover more types of data and functions. A critical long-term benefit comes from the open standards for storage and transmission of data used by the Internet, replacing the 'Tower of Babel' created by proprietary EMRs in the 1970s and 1980s [7]. Finally, recent developments in Web browsers have added improved graphics, audio, and video that can present almost any medical data from heart sounds to CT and ultrasound scans. Such capabilities enable EMRs to integrate multimedia data obtained during telemedical consultations (see Chapter 3.3) and constitute an additional benefit of the Internet and the Web for clinical data management (see Box 2). Perhaps surprisingly, the hardest part

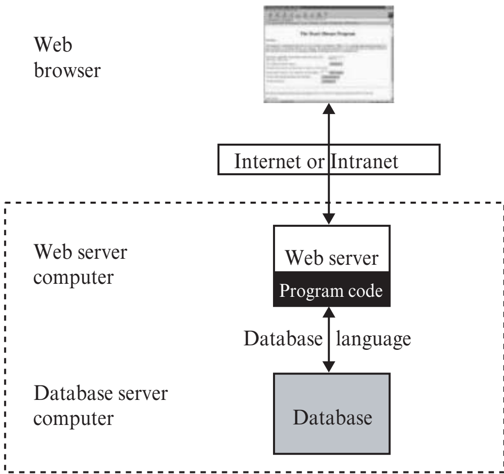

Fig. 1 Typical design of database-backed Web site.

Box 2 Benefits of the Internet and the Web for clinical data management

- Wide availability
- Simple, familiar user interface
- Ease of scaling up a small system to cover more sites and clinical material
- Open standards for information exchange
- Easy display of graphics and multimedia
- Rapid development
- Good security tools

remains the collection, coding, and organization of textual data about patients (see Box 3).

Security, confidentiality, and legality

A major barrier to acceptance of Web-based medical records is concern that confidential data will fall into the wrong hands. The development of systems to handle credit card transactions has provided tools to encrypt data transmitted over the Web, such as the Secure Socket Layer protocol (SSL) [9]. Great care is required, however, to ensure that authorized staff protect data and passwords, as a security system is only as strong as the weakest link [10–12]. The diabetic medical

Box 3 Data entry problems

Getting clinical data into electronic records, whether Internet-based or not, has proved troublesome. The basic data entry options are:

Free text:

- quick and flexible to record
- difficult to analyse and search

Structured:

- involves the use of check boxes and drop-down lists for each clinical item
- works well for simple cases but can be very restrictive in complex cases
- multi-layered menus have few friends and are therefore rarely visited!

A compromise is to structure major items such as problem and medication lists while allowing the core clinical history and examination to be entered as free text. Techniques to aid the data entry process include:

- programs to convert free text into structured problem lists and codes
- voice recognition [8]
- pen-based data entry
- flexible data entry at the point-of-care using handheld and wireless devices

record in Salford (Manchester, UK) is an example of a successful, encrypted, Web-based system [13]. Chapter 3.4 covers security issues in more detail.

A related issue is auditing medical record entries to log any access or corrections. This is essential as we move to paperless practices where the EMR is the legal document [14]. Correctly designed systems keep a record of the date, time, and user identity of any entries in the record. If an entry is changed a permanent record must be kept of both the original and new value. Part of the evidence used to convict British general practitioner and murderer Harold Shipman came from entries in his electronic record [15]. These included symptoms and signs dated during the patients' last year of life that were shown in fact to have been entered after their deaths. A similar system at Boston's Beth Israel Medical Center detects if staff are inappropriately reading the records of hospital employees or VIP patients [16].

Interoperability

The greatest benefit of a networked system is seen when there is a critical mass of users and data. One central database is more efficient and easier to set up, but the piecemeal nature of computerization means that important data may reside in many different 'legacy systems' of different ages, such as a clinical chemistry laboratory database. The Internet was developed to handle such situations, but clinical data must also be translated into a standard coding format such as Clinical Terms version 3 (formerly the 'Read Codes') [17], SNOMED, HL7 [18] or recently, XML [19,20]. There is a substantial literature on this important issue [2,3,21]. The W3-EMRS was developed to combine data on patients stored at three different Boston hospitals into one Web display [5]. Due to the inevitable politics of sharing data between competing institutions it is currently used to connect together two different systems in sister hospitals [16]. Maintaining control of local data is often preferred to the more efficient centralized system, but it is important to avoid having multiple (possibly different) copies of the same information.

Patient-controlled medical records

The Web has profoundly increased the availability of medical information to a large part of the population. Paradoxically, the only medical data that are not available to a person is his or her own medical record. With mobile populations, and the involvement in a patient's care of multiple specialists in different hospitals, there may be no one person who has the full picture. One radical approach to this problem is to give patients their own lifelong medical record, accessible over the Web [11].

Physicians would be allowed access to view previous data or enter new clinical assessments but the patient would be the gatekeeper. This solves many of the problems with clinical data management including fragmentation of data, loss of access when the patient moves home or travels, decisions about which organizations or individuals can view the record, and misunderstandings about what the patient knows. With suitable tools to explain laboratory results and medical terminology, it should be possible for patients to keep better track of their condition and help detect errors and omissions. For chronic diseases such as diabetes or hypertension, the ability to track day-to-day changes in the status of the patient can allow detection of abnormal trends and early notification of the physician or nurse through e-mail. Guardian Angel is one of the original proposals:

http://www.ga.org/

A prototype system has been developed at Boston's Children's Hospital and will be made available to the parents of newborns to form the start of a lifelong medical record [22]. It currently allows parents to access throat-smear results after their child has been seen in A&E. Participating parents are given a URL, user name, and password and told to check the site after 2 days. Explanations are provided for abnormal results and the physician is also informed directly (Fig. 2). Software is being developed to connect to other laboratory databases and to allow older records to be scanned or faxed into the system (a useful stopgap that does not, however, allow searching or processing of the data).

Major technical challenges include security and access controls, patient-friendly user interfaces, and methods to store data reliably long term, potentially for decades. Other hurdles are political and commercial (who owns the data), and practical (how do we teach patients to manage this new responsibility, and avoid increasing stress and fears from reading their doctors' hypotheses). Studies have shown that patients are able to

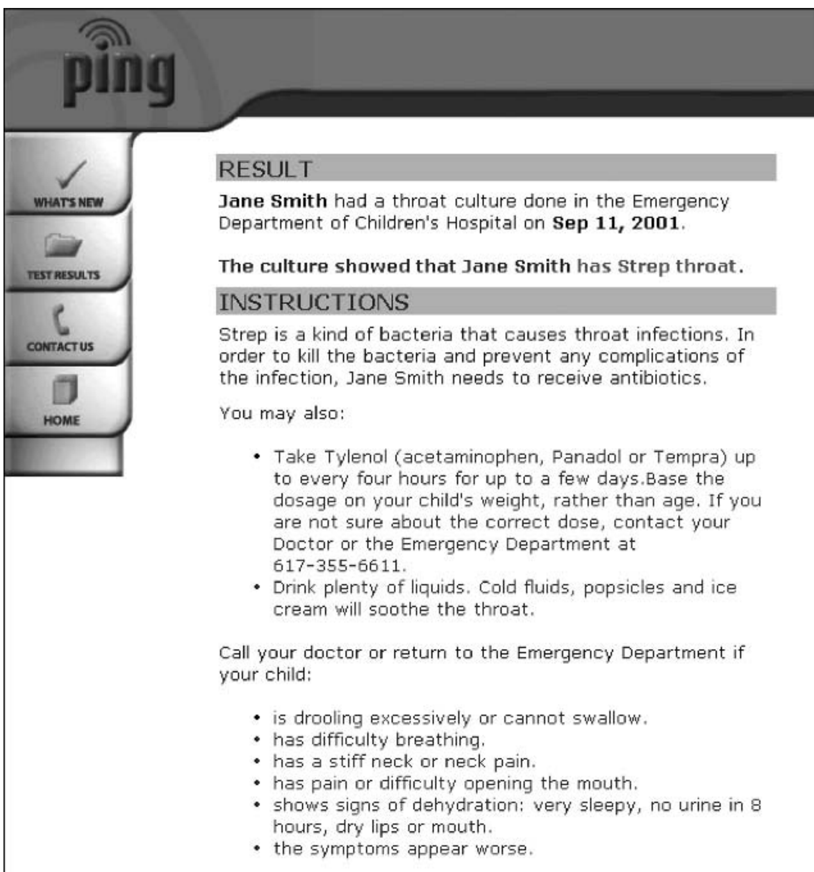

Fig. 2 Prototype systems provide patients with access to their own laboratory results and explanations of the findings.

accurately enter parts of their history into a computer [23]. The personal record is likely to profoundly alter the doctor–patient relationship, and should in time reduce errors and misunderstandings, and even help to detect certain cases of malpractice. A number of commercial systems are now offering patient access to their health records, such as WebMD with 'My Health Record':

http://my.webmd.com/my_health_record

Plans to offer patients electronic access to their records were announced in the UK's National Health Service information technology strategy [24]. Initial experiments [25] concentrated on allowing patients to view their records using Web-based browsers running on computers at practices connected to NHSnet (p. 16), rather than via the Internet.

Decision support systems

Decision support is a general term and can include textbooks and paper flow diagrams. Here we will discuss three main categories of computerized decision support systems: alerts and reminders based on simple rules, prediction models, and differential diagnosis systems. These approaches often merge, however, especially in larger systems.

Rules, guidelines, and alerts

Clinical guidelines have been around for decades in the form of written protocols and branching flow diagrams. These rules can be automated in computer programs and applied to data in the EMR. Simple rules of this sort have been shown to be effective in enhancing clinical performance e.g. by alerting the physician to possible problems with a drug prescription or reminding them of the need to screen certain patients [26,27]. The design of the rules is fairly simple in most cases but integrating them into the medical record system so that it responds correctly to data can be quite challenging. This approach works best if physicians enter their own data, particularly for ordering drugs or investigations [28,29]. Then an alert can be displayed immediately (for example indicating that the patient is allergic to the drug being prescribed) and corrective action taken by the physician. An example is the PRODIGY system, providing prescribing support functions:

http://www.prodigy.nhs.uk/

Alternatively, an e-mail message can be generated when a particular combination of events occurs, for example a falling CD4 count in a patient with HIV [30]. Being able to generate such advisory messages is one of the most important benefits of an EMR in which data is structured and coded rather than entered as free text. Internet-based EMRs have the additional benefit of allowing the integration of data from multiple databases such as laboratory systems. The problem with this approach is that rules and guidelines have to be carefully designed and tested in a particular medical record system, and may not transport to other systems [31] or scale well. A few clear messages generated by a handful of well-designed rules may turn into a cacophony of contradictory and misleading advice if hundreds of rules are available. At present rule-based alerts and reminders are the best validated, evidence-based approach to decision support [11,26].

Prediction models

A common type of decision support system is designed to predict the likelihood (or risk) of a patient developing a disease, such as ischaemic heart disease, over the next 10 years. Prediction models are usually based on statistical analysis of patient characteristics that are hypothesized to be associated with the risk of adverse outcomes, such as age, gender, weight, smoking, etc. A number of techniques have been developed to generate models from clinical databases. These include automatic classification trees [32], artificial neural network programs [33], and logistic regression models [34].

Box 4 shows an example of a logistic regression model based on a database of patients in the Framingham heart study [35]. The result is a mathematical equation that can be incorporated into Web sites or other computer displays. This model calculates the probability of a patient developing ischaemic heart disease and a related model has been shown to be effective in a number of different communities [36]. A Web-based demonstration and detailed equation is available [37]:

http://medg.lcs.mit.edu/projects/heart-home/coronary-risk.html

Some sites now offer prediction models for direct patient use:

http://www.intelihealth.com/IH/ihtIH/WSIHW000/8059/8174.html

Many prediction models are, however, very specific to the data they were generated from, and cannot automatically be applied to a different patient population. It is also necessary to have substantial amounts of data to generate and test prediction models [38]. Therefore users should look carefully at any model to ensure there are links to thorough prospective evaluations of the model's accuracy and generalizability.

Box 4 The new Framingham logistic regression model for predicting cardiac risk

Sex:

Age:

If female: Menopause

Have you had a heart attack, angina, or ischaemic stroke?

Are you diabetic?

Are you a smoker?

Do you drink alcohol? less than 5 oz/wk 5 or more oz/wk

Systolic blood pressure

Anti-hypertensive therapy?

Cholesterol: Total, HDL, triglycerides

Differential diagnosis systems

The key focus of early research in medical computing was the writing of programs to perform differential diagnosis. These systems use a variety of reasoning mechanisms including sets of rules, pattern matching, and methods to calculate the probability of multiple diagnoses [39]. They were mainly based on expert knowledge from clinicians and sought to rival specialist clinical expertise, hence were often called expert systems. The results were mixed, often reasonable for narrow specialist areas but disappointing for general diagnosis as required in general practice. In one study, four well-designed systems (Dxplain, Iliad, Meditel, and QMR) were tested on 105 different medical teaching cases. These systems listed the correct diagnosis 25–38% of the time [40]. Despite this a subsequent study showed that two of these programs, 'Iliad' and 'QMR', could improve the quality of differential diagnoses generated by medical students and physicians [41]. A more recent system incorporating new diagnostic methods, and limited to the field of cardiovascular medicine, achieved better results. The Heart Disease Program (HDP) was tested on 114 actual cardiology inpatients, and listed the correct diagnosis 60% of the time, compared to 39% for the trainee physicians [42]. Data entry is a significant barrier to the use of such systems, however: for the HDP it took a median of 15 minutes per case, and many systems take longer.

HDP:

http://medg.lcs.mit.edu/projects/hdp/hdp-demo-tab.html

Dxplain:
http://www.lcs.mgh.harvard.edu/dxplain.htm

The importance of these general diagnosis programs is that they attempt to build a complete picture of the patient's patho-physiology rather than focus on one small part of the problem. As more clinical data and diagnosis rules become available within EMRs, it will be necessary to balance conflicting recommendations or treatments strategies for each patient, likely favouring such a 'big picture' approach to diagnosis.

Conclusion

The availability of sound clinical evidence combined with comprehensive and accurate clinical data collection has great potential for improving the quality and consistency of healthcare. The Internet provides excellent tools to achieve this goal but much work needs to be done to simplify data entry and ensure that different systems talk to each other. These tools can also be combined with the personal medical record to provide advice and support directly to patients. As with any medical device or intervention, all computerized tools must be carefully evaluated to ensure that they improve healthcare quality and do not just increase the costs, or waste doctors' time [43].

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3.3 Telemedicine consultations

Richard Wootton

Introduction

Telemedicine is the delivery of healthcare and the exchange of healthcare information across distances (the prefix '*tele*' derives from the Greek 'at a distance'). As such, it encompasses the whole range of medical and health-related activities, including diagnosis and treatment, management and prevention of disease, and education of professionals and consumers alike, where distance is involved.

The idea of telemedicine is not new and consultations at a distance have taken place for many years. Since the early 1900s ships at sea have used radio to obtain medical advice for seafarers and the ordinary telephone was, and still is, used extensively for consultations in which the patient and doctor are in different places. More recently, the Internet has been used for similar purposes.

The topic of 'telemedicine consultations' (teleconsulting) covers a wide range of applications, telecommunications media, and participants. It is helpful to consider the subject in terms of the type of consultation, the purpose, and the participants.

Type of consultation

A common example of a consultation occurs when a doctor seeks the opinion of a specialist. However, a consultation could also be said to occur when a healthcare worker seeks information from a database. That is, the term 'consultation' can be thought of in general terms as a process that results in the transfer of information from a source of expertise to some kind of client requesting it.

Consultations can take place in two fundamentally different ways. These are when the interaction takes place in real time, and when it is asynchronous (see Table 1).

Table 1 Teleconsultations may be in real time or asynchronous

Type of interaction	Characteristics	Examples
Real time (or online or synchronous)	Participants, who may be separated geographically, can interact instantaneously	Telephone or video conference
Asynchronous (or 'store-and-forward' or offline)	Participants can only interact by leaving messages for each other	E-mail or voicemail

Real-time consulting

A face-to-face meeting in a hospital corridor is a real-time consultation. To hold the same meeting at a distance requires equipment, the details of which will depend on the type of information being transferred. Consultations may involve the transfer of:

- data, including text
- audio
- still images
- moving images (video).

In the case of audio, for example, a radio or a telephone will be needed. In the case of moving images, a video link of some kind will be required. Figure 1 shows a real-time consultation in progress, using videoconferencing equipment. Note that in this case, since the required data transmission rate cannot be achieved consistently via the Internet, ISDN lines (p. 17) connect the equipment.

In cases where the additional information conveyed by a picture is important (e.g. ultrasound video images) then real-time teleconsulting can be very successful [1]. However, the use of the humble telephone is underrated in telemedicine. Telephone follow-up of hospital outpatients has been shown to have advantages in some specialties [2] and telephone triage has proved popular with members of the public, even if it is not strictly cost-effective [3]. The cost of telephone usage is likely to continue to fall. The adoption of Internet telephony, or 'voice over IP', as quality-of-service issues are addressed, will also have interesting implications for telemedicine.

Asynchronous consulting

When two parties cannot arrange a real-time meeting, they may resort to asynchronous meetings instead. The equipment required for asynchronous

Fig. 1 Real-time telemedicine as a decision-support aid.

consulting also depends on the type of information that is being transferred. For example, stored telephone messages (voicemail) can be a useful technique if visual information is not required. An increasingly common method of consulting is the use of e-mail, supplemented by still images captured with a digital camera. The equipment required amounts to nothing more than an Internet-connected PC and a suitable camera (see Fig. 2).

Pros and cons

The two different approaches to teleconsulting have their own advantages and disadvantages. Real-time interactions allow more rapid problem solving—there is no delay while the sender waits for the other party to collect their message and reply. In the case of a consultation between a specialist and a GP, the specialist can ask specific questions and receive immediate replies, similarly to an ordinary consultation by telephone. There are also educational benefits for those involved. However, a major disadvantage of this form of interaction is the necessity for both parties to be available simultaneously, which often requires prior scheduling and is usually inconvenient. In addition, the cost of the technology required for a real-time interaction will probably be higher than for an asynchronous one. For these reasons, there is likely to be a continued growth in offline teleconsulting,

Fig. 2 Digital camera and e-mail for asynchronous teleconsulting.

in particular, asynchronous teleconsulting using the Internet. Real-time teleconsulting is considered in more detail elsewhere [4].

Purpose

The purpose of a teleconsultation may be:

- treatment
- education/information provision
- management/monitoring
- diagnosis.

Treatment

There are few examples of treatment being administered directly through the Internet, such as control of surgical robots from a distance. This will probably continue to be the case because of the difficulties in guaranteeing the required standard of service in the case of a public, shared communications medium. However, the Internet has successfully been exploited for treatment in psychiatry where the demands on the communications network are much lower. One example is the treatment of post-traumatic stress using a Web-based service [5]. Another is the use of the Internet for education to combat addiction [6].

Education/information provision

The role of the Internet in supporting undergraduate and postgraduate medical education is considered elsewhere (see Chapters 4.1 and 4.2). The role of the Internet in providing health information to patients is discussed in Chapter 5.1.

Management/monitoring

Almost ubiquitous coverage makes the Internet valuable for routine patient monitoring or for patient management purposes. Examples include:

- **Diabetic monitoring** [7]: patients recorded information about their meal portions and blood glucose readings, using a hand-held electronic diary. After transmitting the data to a central server through a telephone modem, the patients received immediate feedback about the carbohydrate, protein, and fat content as well as the calories of the meal. A significant improvement in glycaemic control was achieved during intervention compared to control periods.
- **Care for high-risk infants at home** [8]: a PC with browser and videoconferencing equipment was installed in the homes of families with high-risk infants. A trial showed that telemedicine combined with Internet support for the family allowed earlier discharge to home of low- birthweight infants, and reduced the costs of hospitalization.
- **Home asthma monitoring** [9]: patients used portable spirometers and palmtop computers to record self-testing data, which were transmitted via a Web interface to a central server. Following transmission, the results were available for a physician to review. Feedback was provided to the patient by e-mail.

Diagnosis

There are numerous examples of the use of the Internet for diagnosis, and these are considered in more detail below.

Participants

Teleconsultations may take place between different categories of participants. These include:

- doctor-to-doctor (here 'doctor' means medical practitioner or other health worker)
- doctor-to-patient
- patient-to-patient.

Doctor-to-doctor

Much of the telemedicine work to date has been real-time, using relatively expensive equipment. Perhaps for this reason it has tended not to operate at the level of primary care. Asynchronous teleconsulting certainly has its place, however, and image transfer via the Internet has been used for several years in pathology. For example, staff at the Armed Forces Institute of Pathology in Washington have offered expert advice on telepathology images sent to them by e-mail since 1993 [10]. A similar telepathology consultation centre has recently been established in Europe [11]. All such systems depend on the client capturing an appropriate image before sending it to the expert by e-mail. Although it does not appear to happen very often in practice, there is obvious potential for the wrong opinion being provided if an inappropriate image is sent to the expert. One way of circumventing the problem entirely is to give the expert remote control of the client's microscope, so that the task of image selection can be handled by the expert. Unfortunately this usually requires a high-speed data link to the microscope, which is fitted with a robot control system. However, recent developments suggest that telemicroscopy of a restricted sort may also be possible using the Internet [12, 13].

E-mail transmission of images has also been used successfully to allow assessment of extremity injuries by expert consultants [14]. X-ray images have also been sent via the Web for similar purposes [15]. Work is in progress to establish the feasibility of rheumatology consultations between GPs and specialists, using Web pro formas and e-mail [16].

All of the foregoing are examples of still image transmission. Transmission of cardiac ultrasound images has been demonstrated over distances of up to 2500 km [17]. To avoid the requirement for a high-speed data link, the video pictures were stored first on a laptop computer, and then compressed (by approximately 15:1). The resulting files took 5–10 min to transfer via the Internet.

As one might expect, most of the experience of asynchronous teleconsulting relates to work in the industrialized world. An elegant example of doctor-to-doctor teleconsulting is the use of Internet e-mail to support practitioners in developing countries. The Swinfen Charitable Trust has provided e-mail links and digital cameras to a number of hospitals in Bangladesh, Nepal, and the Solomon Islands, with which clinical queries are answered by a panel of specialists around the world who have agreed to donate their expertise [18]. For further details, see:

http://www.coh.uq.edu.au/swinfen/

Finally, other, simpler forms of teleconsulting amongst peers are also possible, such as medical electronic mailing lists (see Chapter 2.1).

Doctor-to-patient

There are many examples of direct patient consulting via the Internet, mainly from the USA. These usually operate by e-mail. It is still too early to evaluate the success of this form of consulting, either in clinical or commercial terms, although there is an obvious demand for it from the general public (something which perhaps reflects poorly on their perceptions of the conventional forms of consulting). One such company, which has made a particular effort to establish an ethical service, is Doctor Global Ltd (see Fig. 3). This service allows patients to request an online consultation from a named doctor; i.e. there is accountability. Patients complete a structured

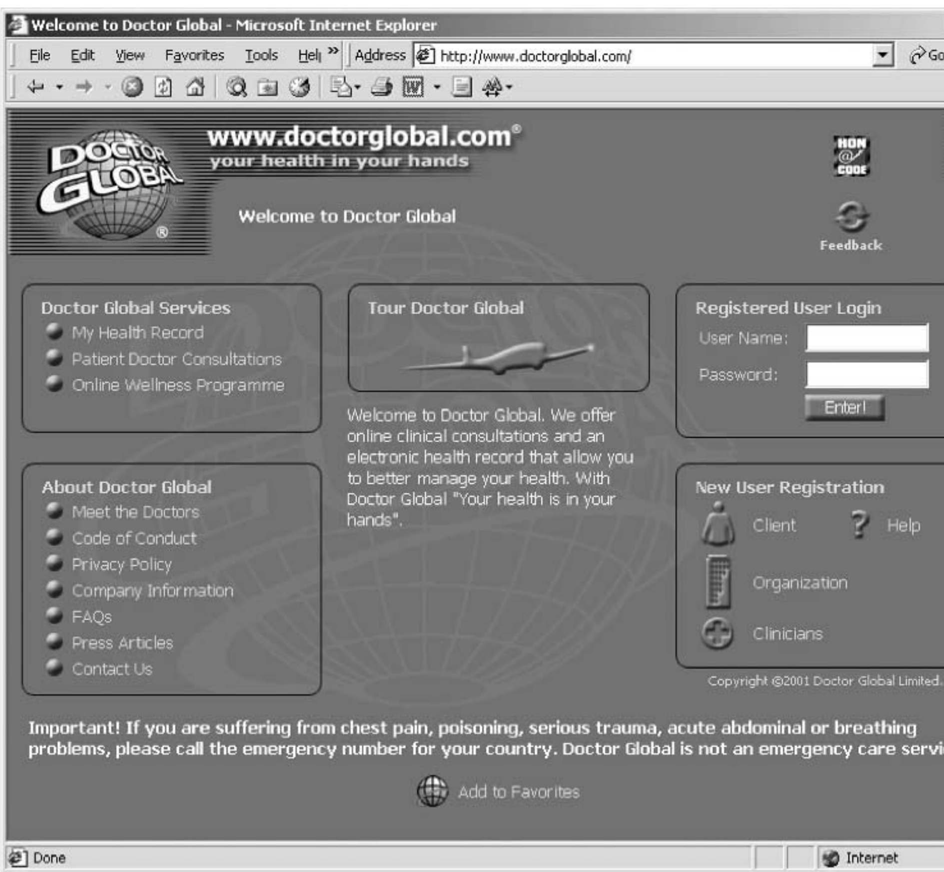

Fig. 3 Doctor Global, a Web-based doctor-to-patient teleconsulting service.

'interview' by e-mail and there is a guaranteed speed of response:

http://www.doctorglobal.com/

Patient-to-patient

Valuable peer support can be obtained via the Internet. See Chapter 5.1.

Medico-legal issues

There are reasonable concerns that exchange of health information via the Internet could lead to breaches of security or patient confidentiality. These might arise during the processing of the data, or during its transmission. In the UK the Data Protection Act (1998) regulates the processing and storage of personal data, providing special protection for sensitive personal data such as health information. Processing this sort of information requires the unambiguous informed consent of the subject, amongst other safeguards.

In the UK the Interception of Communications Act (1985) makes it an offence to intercept a communication intentionally during its transmission through a public telecommunications system. Nonetheless, it is prudent to ensure that communications through relatively insecure channels such as the Internet do not contain information that would allow an individual patient to be identified. Issues around security and confidentiality are discussed further in Chapter 3.4.

Another concern for practitioners engaged in teleconsulting are the legal consequences if something goes wrong. What is the position if a misdiagnosis occurs, for example, during a teleconsultation? In the UK a doctor would not be guilty of malpractice if he or she had acted in accordance with a practice accepted as proper by a responsible body of appropriate professionals—this is known as the Bolam test [19]. Malpractice would therefore be judged by reference to acceptable standards of practice. In a developing field such as telemedicine, formal standards are largely in the future, which makes the conduct of research trials essential.

Many of the answers to questions about the legal and ethical aspects of teleconsulting will ultimately become clear only when settled by the courts. However, persons engaged in teleconsulting can minimize the chances of medico-legal complications if they behave in a prudent manner [20].

The business case

There are no insuperable technical or medico-legal barriers to teleconsulting. As described above, its feasibility has been demonstrated in a wide range of circumstances. User-satisfaction surveys regularly show that it is popular with patients, and to a lesser extent with healthcare professionals. However, teleconsulting is not going to be implemented on a wide scale until there is evidence for its cost-effectiveness. At the very least we need to know that teleconsulting is no more expensive than conventional consulting and equally effective clinically. Such evidence is still lacking, although information is slowly being published.

Teleradiology is generally considered to be the most mature part of telemedicine, and the business case is clear. For small peripheral hospitals it will usually be cheaper to transmit X-ray images to a centre of expertise for reporting, rather than retaining a radiologist on staff, or using the services of a visiting specialist. Not unexpectedly, the relative merits of the three different approaches depend on the actual workload. Because of the equipment investment, a minimum number of cases is required before teleradiology becomes cheaper than reporting films on site [21].

In Finland a referral system using electronic messaging (similar to e-mail) has been employed by GPs since the early 1990s. Studies show that the direct cost of an outpatient clinic visit in internal medicine is seven times greater per patient than for an e-mail consultation [22]. The use of electronic referrals avoids outpatient visits in a significant proportion of cases and improves the overall productivity of the hospitals concerned.

Conclusion

As described above, a wide range of consultations have been carried out using the Internet. What general principles can be discerned? Such activities take advantage of two important characteristics of the Internet:

- ubiquitous availability
- low-cost access.

This makes the Internet a highly suitable communications medium for many kinds of distance consulting, including education and information provision. However, teleconsulting using the Internet may not be appropriate if there is a special requirement for:

- Speed; i.e. a high bandwidth connection is necessary (e.g. to transmit video pictures).
- Security/confidentiality (which is difficult—though not impossible—to ensure on a public, shared network).

If the criteria of high speed and secure access are judged sufficiently important, then the use of private networks may be justified. Note, however, that the implementation of a large-scale, private network for the UK NHS (NHSnet) has not been judged to be successful or cost-effective [23].

The Internet is not a panacea, either for telemedicine in general or for teleconsulting in particular. Despite the lack of evidence for cost-effectiveness, it seems reasonable to expect continued growth in the use of the Internet for online education and information provision, as well as for various kinds of consultation. The place of the Internet in healthcare has yet to be established definitively—but seems likely to be important. Sources of further information about teleconsulting are given in Box 1.

Box 1 Sources of further information about teleconsulting

Telemedicine Information Exchange	http://tie.telemed.org/
Journal of Telemedicine and Telecare	http://www.roysocmed.ac.uk/
Telemedicine Journal	http://www.liebertpub.com/
SatelLife	http://www.healthnet.org/

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3.4 Security, privacy, and confidentiality issues

Grant Kelly and Bruce McKenzie

In this chapter we introduce the issues around protecting information about patients and related data sent via the Internet. We begin by reviewing three concepts necessary to any discussion about data security in a healthcare environment: privacy, confidentiality, and consent.

Privacy

'Privacy' is a vaguely defined term that, in an online context, includes the right of an individual to:

- Determine what information is collected about them and how it is used. Sometimes we are not aware what data are being collected about us (e.g. via 'cookies' on a Web site—see Glossary) or how it may be used. Registering with a Web site (i.e. giving your name, e-mail address, medical registration number, etc.), for example, may enable that site to keep track of what you—a readily identifiable individual—view or spend online. Such information could be passed on to third parties. Some sites publish 'privacy policies' in an attempt to inform users and reduce the chances of patients or healthcare professionals placing their privacy at risk.
- Access information held about them and know that it is accurate and safe.
- Anonymity (e.g. not having your Web-browsing habits tracked).
- Send and receive e-mail messages or other data (e.g. credit card numbers) that will not be intercepted or read by persons other than the intended recipient(s). Encryption (discussed below) is one way of ensuring this.

For more information about privacy on the Internet, see Box 1.

Box 1 Privacy resources on the Internet

Platform for Privacy Preferences Project (W3C):
http://www.w3.org/P3P/

Understanding security and privacy (Netscape):
http://home.netscape.com/security/basics/

Privacy and security fundamentals (Microsoft):
http://www.microsoft.com/privacy/safeinternet/

e-Health Code of Ethics (Internet Healthcare Coalition):
http://www.ihealthcoalition.org/ethics/ehcode.html

Statutory and professional considerations

Confidentiality

The ethical duty of confidentiality is defined by the British Medical Association as 'the principle of keeping secure and secret from others, information given by or about an individual in the course of a professional relationship' [1]. In the UK the legal duty of confidentiality is underpinned by the Data Protection Act (1998), regulating the processing of information ('data') that could lead to the identification of individuals—including its collection, storage, and disclosure [2]. To ensure the protection of confidentiality in an electronic environment the General Medical Council (GMC) recommends that doctors should [3]:

- Make appropriate security arrangements for the storage and transmission of personal information.
- Obtain and record professional advice given prior to connecting to a network.
- Ensure that equipment, such as computers, is in a secure area.
- Note that Internet e-mail can be intercepted.

Consent

'Consent' for our purposes is the means by which we are authorized by an individual to process information about them based on their informed understanding of what we intend. To include identifiable patient information in an e-mail message or on a Web site in the absence of a patient's express consent would constitute a breach of confidentiality. Obtaining consent should involve making the patient aware of any risks to his or her privacy and the arrangements in place to protect it. Identifiable patient information could therefore be transmitted via the Internet with the informed consent of the patient, and with regard for the advice of the GMC (or equivalent professional body) and established principles such as those of Caldicott (see Box 2) and the Data Protection Act (see Box 3).

Box 2 Caldicott Principles

In relation to identifiable patient information:

- Justify the purpose(s) for using confidential information.
- Only use it when absolutely necessary.
- Use the minimum that is required.
- Access should be on a strict need-to-know basis.
- Everyone must understand their responsibilities.
- Understand and comply with the law.

For further information, see:

http://www.doh.gov.uk/nhsexipu/confiden/report/index.htm

Box 3 Data Protection Act Principles

Personal data must be:

- fairly and lawfully processed
- processed for limited purposes
- adequate, relevant, and not excessive
- accurate
- kept for no longer than necessary
- processed in accordance with the data subject's rights
- secure
- not transferred to countries without adequate protection.

For further information, see:

http://www.hmso.gov.uk/acts/acts1998/19980029.htm

Information that cannot result in identification of an individual may have been 'anonymized' (where identifiers are removed) or 'aggregated' (where data from a number of individuals are summed). The requirement for consent to transmit or place such information online in this event is less certain, but perhaps prudent, although such non-personal data are not subject to legal restriction (i.e. the Data Protection Act).

Where is the enemy?

Security tends to be the progeny of scandal. A few years ago, a bank in the Midwest USA purchased a hospital along with its medical records. It coolly compared the records against its personal bank accounts, and foreclosed on the loans of all account holders with a diagnosis of cancer. It was business-like, simple, ignorant, cruel, and an example of the damage that medical data can do in the wrong hands. Today computer 'security' is typically perceived to mean keeping hackers (those attempting unauthorized computer access) and other troublemakers from your private data. But what if such troublemakers are part of the system, or even own it?

Clearly, a simple 'cops and robbers' model does not offer enough protection, highlighting the need to ensure data security at multiple levels. The risks are internal, external, and random, and can result in data damage, falsification, loss, or leakage. It is helpful to imagine your connected system as resembling a data stream right from your keyboard to that of the recipient, and to consider the risks along the way.

Protecting local data

Even before you connect, your data is at risk. Clearly you don't want your Internet-linked clinical system or home computer to be burnt, flooded, stolen, hit by lightning, damaged by third party software, or accessed by untrained staff or inappropriate people. You will need to back it up properly, look after the backups, and periodically reconstitute the system from backups so that you know it will work if you ever need it.

Ensure that your terminal or PC is left logged out when you are apart from it for a reasonable length of time. Most systems can be set to log out automatically by default under these circumstances and this makes good sense. Make sure that your screen shows information only to people who are entitled to see it.

If you connect to the Internet at work (e.g. via NHSnet—p. 16) you may wish to ensure that your e-mail server (p. 9) has central control over a shared address book, with limited access rights to alter it and to reply to external addresses. Doing so prevents staff from using e-mail at work to converse with friends—which not only reduces working efficiency, but also provides a means of access for viruses (see below) and other unwelcome material.

Appropriate advice and countermeasures are detailed elsewhere [4,5], enabling you to develop robust protocols to preserve the integrity of your local system. Further NHS-specific guidance is available from the NHS Information Authority Web site:

http://www.standards.nhsia.nhs.uk/sdp/

The risks of connecting

Open systems: the Internet

Linking computers together means that you can access other people's data, but it inevitably follows that this allows others to access data on your own system. Until such time as individual computers or networks are linked together they resemble 'islands' of electronic data. Security on a data island is simple: reassuringly firm borders trap all unauthorized entrants. However, when you build bridges by creating a network link this approach on its own is inadequate. When a computer connects to the Internet, it loses its island status by compromising the integrity of its 'borders'. Any potential benefits of connecting must be weighed against the risks to your own data. In a healthcare environment, this data is often of a highly sensitive nature. Even connecting a home computer may expose data, such as banking details, which you would prefer to remain private.

Closed systems: the intranet

Why connect in such an open way? Why not restrict the connection to 'friends' only? In other words, why don't we connect only to trusted computers over trusted network links, thus extending our own trusted computing base? Enter the intranet, introduced in Chapter 1.2. Intranets are suited to smaller organizations with enforced security policies and strict personnel control—something not always attainable within a large health service. They are by nature restrictive, as security through exclusion conflicts with the potential of a network to enhance medical communications in a connected world. Intranets may provide a false sense of security: as the electronic thief attacks the weakest link in the chain, security measures must reflect this. A properly secured intranet therefore demands such things as locked rooms for terminals, physiological checks for terminal access, and armoured, pressurized cables to detect cable tapping.

Virtual private networks

Blurring the divide between public and private networks, a virtual private network (VPN) uses a 'tunnelling protocol' and encryption (see below) to send private data through public networks such as the Internet. Although communicating parties do not need to invest in a private network infrastructure, they have no control over the network used and no guaranteed standard of service. The lack of interoperable implementations has been the main impediment to the deployment of VPNs to date [6].

Firewalls

Just as you wouldn't allow anybody to listen in to your telephone conversation, so you need to care for your Web browsing sessions and e-mail exchanges. For this purpose you need a firewall, designed to prevent damage to your system. These software or hardware devices operate by recognizing the IP address (p. 10) that a message or system query comes from, and only allowing past those that are recognized as 'good' or trusted. With the advent of higher-risk 'always on' Internet connections, firewall solutions of varying complexity are readily obtainable.

Protecting data in transit

Whether you are connected to NHSnet or the Internet the security threats to your data in transit are the same; data may be subject to loss, late delivery, damage, or attack. Against loss or lateness, there is little the individual can do, but damage or attack can be dealt with. You should assume the wires (or other network infrastructure) could be got at—as indeed they can—and thus must give your data a metaphorical envelope to maintain its integrity and privacy. This is precisely what cryptography can do.

Message encryption

A popular technique for protecting messages in transit is so-called asymmetric public-key infrastructure (PKI) cryptography. Alice and Bob (who wish to exchange messages) each use an algorithm based on very large prime numbers to develop two separate but related numbers, by way of typing in a pass-phrase. Both end up with an alphanumeric code that forms their 'public' key (which they publish), and an alphanumeric code that forms their 'private' key (known only to themselves and represented by their pass-phrase). If Alice wishes to send a message to Bob, she finds his public key (typically from a directory), writes her message, and encrypts (addresses) the data to Bob's public key, thus producing a unique set of digital data. Bob receives this in encrypted form and uses his private key to extract the data back into Alice's original text message. This process is illustrated in Fig. 1.

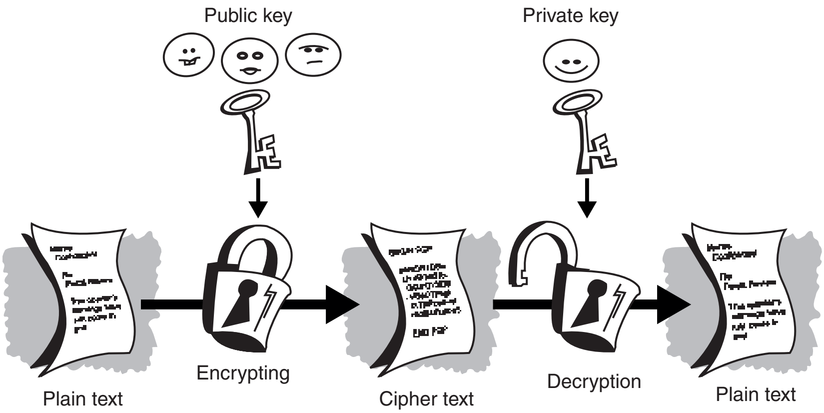

Fig. 1 Using a public/private key pair to encrypt messages helps ensure protection during transit.

In use, this is easier than it sounds, and confers integrity (the data haven't been manipulated), authenticity (the identity of the sender is known), non-repudiation (the data can't be disowned) and privacy on the data. Any attempt to interfere or damage the contents messes up the mathematics, and the message becomes unintelligible, thus warning the recipient not to trust it. Provided the verification of the identity of the key-holders is carried out in a dictatorial fashion, the origin authentication of the message is also assured. If only Alice knows the private phrase key to make an exchange work, then only Alice can have sent the message.

Authentication and privacy of e-mail via encryption is offered by Pretty Good Privacy (PGP) and Secure Multipurpose Internet Mail Extensions (S/MIME), both proposed Internet standards.

Pretty Good Privacy (PGPi Project):
http://www.pgpi.org/

S/MIME (RSA Security Inc.):
http://www.rsasecurity.com/standards/smime/

Browser encryption

As we move towards a browser-accessible type of electronic patient record there will arise a need to protect the exchange of data from leakage and attack. A precedent has been set by the widespread practice of Internet banking and commerce, which out of necessity involves transmitting confidential information. The *de facto* Internet standard for encrypting Web-based information interchanges is Secure Sockets Layer (SSL), more recently known as Transport Layer Security or TLS [7]. SSL/TLS can also be used to encrypt e-mail messages. It uses a symmetrical one-time electronic key that works between the browser and the server for as long as the connection is open. When the session ends, the encryption dies with it, and thus it depends largely on its length of key structure and short time of operation for its safety. SSL/TLS is more demanding on server resources than non-encrypted connections, so secured Web pages are often slow to display.

Assurance of identity (authentication) on the Web presently requires the use of a certificate supplied by a third party Certificate Authority, such as VeriSign Inc.:

http://www.verisign.com/

UK readers should note that the NHS has its own cryptography strategy:

http://www.doh.gov.uk/nhsexipu/strategy/crypto/index.htm

Receiving data

Digital signatures

There is a simpler PKI process using the same algorithms referred to above to 'sign' a message whereby the private key of an individual can be used to 'hash' the message. This can then be verified against the sender's public key. This ensures the data's authenticity and origin without conferring privacy, and is called a 'digital signature'. The process is illustrated in Fig. 2. In the UK the Electronic Communications Act 2000 provides the legal framework for the recognition of digital signatures [8].

What about viruses?

Viruses are small segments of code that have been inserted into computer files, often with malicious intent. An infected file may cause annoyance or the loss of data. In theory, any file you download from the Internet is a potential vector. Viruses may also be present in files attached to e-mail messages (but cannot be transmitted via a text-only e-mail itself). There are a number of antiviral programs available (some are free) that will screen for and help you neutralize infected files on your computer—before they are activated or have a chance to 'replicate'. Some viruses are activated when you use an infected program; others merely require you to view an infected document. Antiviral programs act like the body's immune system in that they are always on the lookout for 'foreign' material—in this case, foreign program code. However, even if your software is regularly

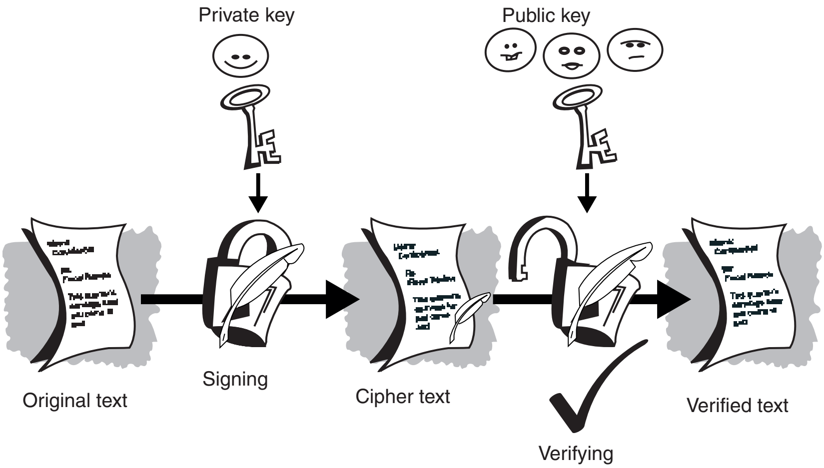

Fig. 2 Using a public/private key pair to verify a digital signature.

updated it won't catch all viruses (especially new ones). Security should be based on the sound sense of not opening e-mails from unknown sources or those containing unusual message headers.

Conclusion

The protection of personal data in a connected world defaults not so much to high-tech applications or hardware, as to careful management of staff and relatively common techniques to ensure the simple, frequent risks are catered for. The determined criminal or government agency will get access somehow, but what matters to doctors is making sure that we take care of the data we collect about patients in a manner appropriate to the twenty-first century.

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4 Using the Internet for medical education

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Undergraduate medical education

- The exponential growth in medical information demands changes in the way medical students are taught and core competencies required.
- Educational goals rather than the technology itself must drive the use of technology in medical education.
- The Internet promotes the development of self-directed learning strategies essential for effective medical practice and provides greater flexibility than traditional methods, allowing students to learn where and when they choose.
- The Internet is used by patients who will increasingly turn to their medical practitioners for guidance about how and where to seek quality information sites. Practitioners require the skills to allow them to respond to such requests.
- Simulations provide opportunities for students to improve skills in controlled and safe environments, and receive immediate feedback.
- Interactive computer games which model complex situations can stimulate learning, increase student involvement, and reinforce previous learning.
- Web-based learning materials are not less resource intensive, rather they change the nature of the education process.

Continuing professional development

- Continuing professional development is not just a matter of keeping up to date, although this is important. Learning new things, developing and maintaining skills, and renewing motivation and enthusiasm for our work are just as important.
- Learning methods that involve passive exposure to information (e.g. attending lectures or reading journals) often have little impact on practice. Active learning methods focusing on skills, problem solving, and personal qualities are more likely to affect what we do.
- The Internet is a rich and flexible medium for active learning that can help us link evidence-based information to practice, allowing us access to it as and when we need it.
- Computer conferencing combines the benefits of small group work with the convenience of distance learning.
- There is a mix of fascinating, boring, free, and subscription-based learning opportunities on the Web: choose with care!

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4.1 Undergraduate medical education

Johanna Westbrook

The Internet provides a powerful tool to assist medical educators and their students. The key to effective use of the Internet (and information technology in general) is to be clear about why it is being introduced and how it will enhance learning. Educators should be able to articulate to students and colleagues how a Web-based learning tool will improve students' learning experiences and outcomes. Educators need to plan carefully when incorporating information technology (IT) in their courses and to devise appropriately rigorous evaluations to ensure that there are measurable benefits. Educational goals should drive the use of technology and not vice versa.

For medical students the Internet provides relatively inexpensive access to overwhelming amounts of information and expertise. Their greatest challenge is to develop navigational and critical appraisal skills that will enable them to become effective learners and practitioners.

Why use the Internet in medical education?

The exponential growth in medical information demands changes in the way in which medical students are taught. Key abilities advocated for future medical practitioners are 'learning to learn' and 'learning for life' [1, 2]. An important factor in the acquisition of these abilities is the development of sophisticated information-seeking skills, essential for evidence-based practice (see Chapter 3.1). Incorporating the Internet in medical curricula promotes the development of such skills and encourages the self-directed learning strategies vital for ongoing learning as a professional [3]. As well as information retrieval skills, students need to manage the quantity, and critically evaluate the quality, of information on the Internet. They may also need to provide patients with basic skills in this area (see Chapter 7.3) [4, 5].

Navigation of the Internet and search skills have become core competencies for medical practitioners as various countries introduce knowledge management systems that provide online access to medical research and policy documents at the point of care. Examples include the National electronic Library for Health (NeLH) in the UK [6] and the Australian Clinical Information Access Program (CIAP) [7]. The Internet provides an important tool to support the problem-based learning approach that has become widespread in medical curricula and that relies heavily on students' information-seeking skills (as opposed to learning information presented in the classroom).

NeLH:

http://www.nelh.nhs.uk/

CIAP:

http://www.clininfo.health.nsw.gov.au/resources.html

Educational advantages of using the Internet

Incorporating the Internet into educational programmes creates flexibility and makes learning more student-centred. Educational enhancement may occur because:

- Students choose the time, place, and pace of learning (asynchronous learning). The range of learning options caters to different learning styles.
- Online education is beneficial to students in clinical settings distant from the university, allowing them ready access to their educators and peers.
- There are greater opportunities for student–educator communication, for example use of discussion groups, online tutorials, and e-mail. This may be synchronous (in 'real time') or asynchronous depending upon the extent to which students are required to reflect upon or research the issues at hand [8].
- The Internet provides an additional strategy for encouraging participation of all students through online tutorials and discussion groups. Individual students are less likely to be dominated by more vocal peers.
- Students gain access to expensive services such as professional journals [9].
- Educational material is kept contemporary. Web pages are easier to update than textbooks.

- In creating a natural trail of association between documents, hypertext links may result in the more efficient assimilation of relevant material than occurs with paper-based references.
- The use of powerful search engines and user-definable topic alerts allow targeting of specific information [6].
- Students can monitor their progress using self-assessment activities. Computer-aided or 'machine-marked' exercises can incorporate answers and links to additional information.
- The Internet enables medical schools to share, exchange, and collaboratively develop educational materials.
- The Internet allows students the opportunity to establish communication with experts and peers. For example, the American Medical Association helps students from around the nation participate in online policy discussions [9].

Computer-assisted learning on the Internet

Computer-assisted learning on the Internet may take different forms, ranging from the simple presentation of course requirements to sophisticated and innovative simulations and interactive learning games which utilize technical features of computers to achieve outcomes not possible by other means.

Computer-based simulations

Computer-based simulations have been widely used for many years in fields such as aviation, yet their adoption within medical education has been limited. Simulators provide opportunities to practice and improve often-complex skills in controlled and safe environments [10, 11]. They provide students with life-like situations and immediate feedback. Computers can be used to simulate clinical encounters [12], interactions and events in a hospital, and the effects on physiological processes of changing different variables [13, 14]. Simulation programs can enhance clinical skills in areas such as surgery [15] and anaesthesia [14, 16]. Advantages of simulations (see Box 1) include limitless practice in times of fewer 'real' specimens [17, 18], reducing student anxiety, and enhanced learning when students encounter real situations [17]. They can play an important role within an environment of reduced resources and limited opportunities for students to meet the full spectrum of clinical cases due to increased specialization and patients' shorter stays in hospital.

Simulations fostering non-clinical medical skills include management of a day surgery [19] and 'IThink!', modelling hospital organizational complexity [20].

Box 1 Advantages of computer-based simulations

'Unlike patients simulators do not become embarrassed or stressed; have predictable behaviour; are available at any time to fit curriculum needs; can be programmed to simulate selected findings, conditions, situations, and complications; allow standardized experience for all trainees; can be used repeatedly with fidelity and reproducibility; and can be used to train both procedures and difficult management situations' [21].

Interactive learning games

Interactive computer games also afford participants opportunities to learn under 'real life' conditions [22, 23]. They help model complexity [24–26], and illuminate behaviour in social systems [27]. They can stimulate learning, increase student involvement, reinforce previous learning, and provide opportunities to test decision-making skills. Peer involvement gives students opportunities to discuss decisions [28]. Education and business have embraced the use of games [29, 30] but there are relatively few examples in medical education. This may reflect concerns that games can trivialize subject material. While games do not always necessitate a computer their intricacies are greatly assisted by IT. Fukuchi *et al.* describe an Oncology Game that improves knowledge of the multidisciplinary nature of cancer management [31]. Topics such as medical ethics that involve confronting issues are well suited to a game approach. Students can try out their ideas in a non-threatening environment and be guided in their thinking by their peers and teachers, an approach found beneficial among high school students [32]. The Health Care Game is an interactive game on the Internet (see Box 2) placing students in the shoes of consumers trying to navigate the health system. It reminds medical students what it is like to not understand how the health system operates or medical terms [33]. Internet games provide the opportunity of linking students into learning communities beyond their immediate settings. For example, teams from different universities have played the Health Care Game. Teams link into local and international community resources via the Web and share this information.

Box 2 The Health Care Game

The Health Care Game [33] is a heuristic Web-based game presenting health-related scenarios involving people from different cultural, socio-economic, and demographic backgrounds (see Fig. 1). Working in competing teams students must interact with the real healthcare system to investigate events and answer specific questions. Teams submit assessment tasks and receive feedback online. The structure of the game incorporates a database of health events from which educators can select, edit, or add depending upon their topic. Thus the game provides a generic structure that fosters information-seeking skills, consumer-centred care, an appreciation of community diversity, and an understanding of the operation of health and community services.

Administration site:
http://www.eng.unsw.edu.au/biomed/health/admin/

Direct access to the game:
http://www.eng.unsw.edu.au/biomed/health/

Both sites may be accessed using the username and password Guest.

Computer-assisted learning packages on the Web suitable for undergraduate medical students include:

Pathology [34]:
http://medstat.med.utah.edu/WebPath/webpath.html

Anatomy and histology:
http://medic.med.uth.tmc.edu/

Anatomy:
http://numedsun.ncl.ac.uk/~nds4/tutorials/

Anaesthesia [16]:
http://www.intuitionmedical.com/

Physiology [35]:
http://phys-main.umsmed.edu/

Interactions with patients (see Fig. 2):
http://musom.marshall.edu/

Gerontology [36]:
http://www2.kumc.edu/instruction/medicine/gerimed/gerimedstart.htm

Radiology:
http://radiology.co.uk/xrayfile/

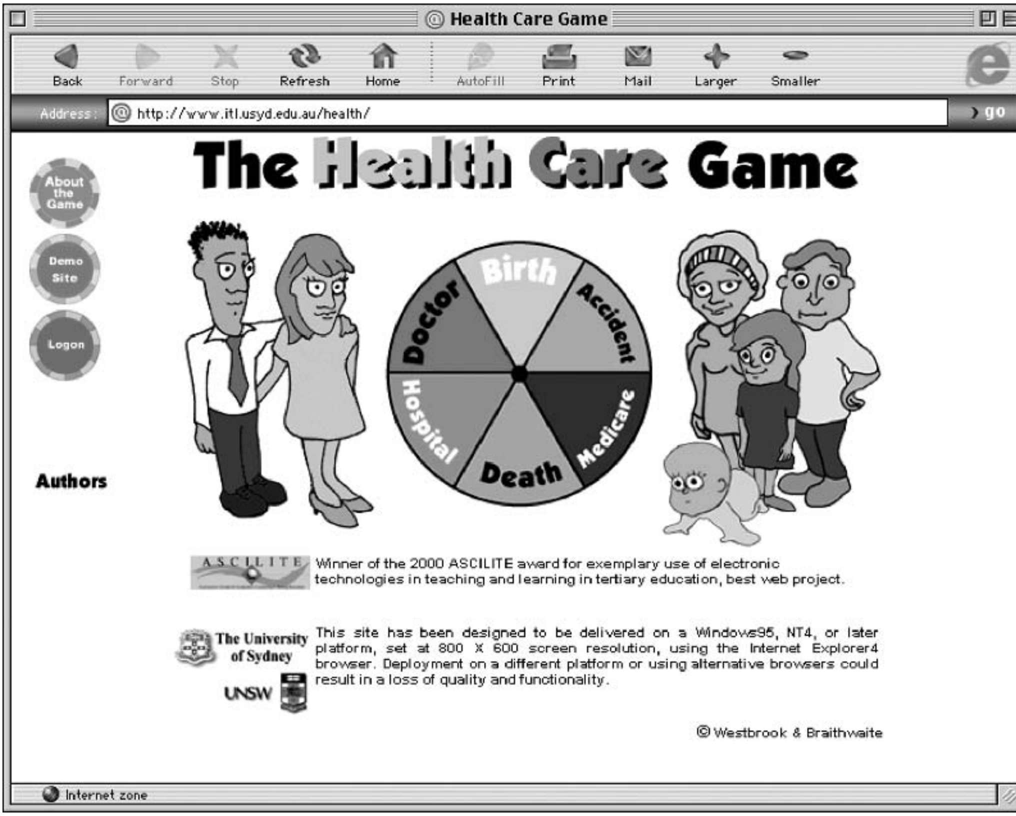

Fig. 1 The Health Care Game develops medical students' information-seeking skills.

Utilizing existing Internet sites and groups

The Internet allows medical students to gain insights into the experiences of people with various illnesses through the Web sites established by medical institutions and support groups for people with particular health problems. The former typically list diagnostic and treatment information that may provide the student with a valuable knowledge base. Support group sites (see Chapter 5.1) contain material ranging from collated reference articles to personal descriptions of illness experiences. These are frequently well documented, and offer students the patient-centred insight into illness that they may otherwise struggle to obtain.

One particularly arresting presentation uses art to interpret the experiences of women with chronic conditions such as fibromyalgia. It shows the weariness of waiting for medical consultations, the depression of living with

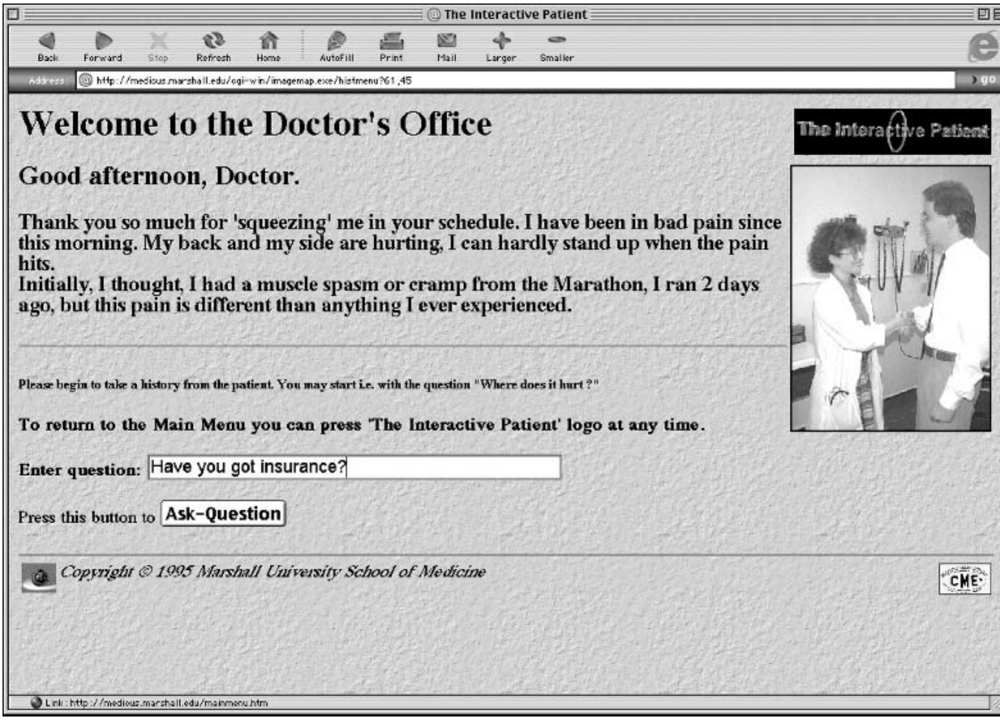

Fig. 2 The 'Interactive Patient' represents an early attempt to bring Web-assisted learning to undergraduate medical education.

pain, and other people's incomprehension of invisible disabilities:

http://www.navigatingthebody.com/

The value of additional insight into patients' points of view is apparent in a book by Nichols [37] presenting enlightening mailing list messages posted by a group of women with multiple sclerosis. Students might be asked to search the Web for sites describing personal experiences with a specific illness, or to subscribe to a patient-oriented mailing list or newsgroup, and to reflect on the implications of their findings for treatment and patient care. Furthermore, acquiring the skill of being able to assist patients to communicate online with others with similar chronic conditions could be a learning objective in itself.

Evaluation of online learning

Evaluations of the use of computer-assisted and online medical education are limited but growing [33, 38]. It is well recognized that evaluators need to adopt multiple assessment methods [39, 40]. Both formative and summative evaluations should be considered [41]. The former provides feedback that can be used to enhance the online course (for example, to make Web site navigation easier). The second measures effectiveness of the course, for example, achievement of specific learning outcomes.

It is initially useful to investigate the extent of students' usage of online materials, for example, as measured by Web site hits, surveys, or observation. What are the causes of low usage? Is the site difficult to navigate? Do some students lack computer skills? Pre- and post-implementation surveys focusing on desired learning outcomes or evaluation of students' skills could be undertaken. Consider measuring changes in students' views, attitudes, and perceptions [42].

Determining the extent to which the Internet contributes to improving learning outcomes may be more problematic (see Box 3). Comparisons of outcomes from traditional course delivery with those obtained from courses incorporating the Internet are another possibility. Comparing new and old versions of a course is difficult because the introduction of technology often results in changes in desired learning outcomes. Using the Internet expands the learning objectives possible. For example, traditional lecture courses often focus on fact transmission (surface learning), while the use of the Internet increases expectations that students will develop information-seeking, critical appraisal skills, and problem-solving skills (deep learning). Methods for assessing such higher-level learning outcomes in undergraduate education are available [40, 43].

Box 3 To what extent does the Internet influence learning outcomes?

Evaluation of the use of the Internet in educational programs is confounded by difficulty in isolating the effects of the Internet from other factors influencing learning [44]. It is often impossible to define the parameters of the Internet as an intervention or to distil whether the intervention is the information, the training of the user, or the ability to analyse and incorporate information into decision-making processes. A multi-method evaluation strategy recognizes this complexity.

Some cautions for educators using the Internet

While the use of the Internet in undergraduate medical education has many benefits that are enthusiastically espoused in the literature, it also has limitations. Hara *et al.* suggest these are almost a taboo topic [45]. Practical and attitudinal issues that educators should consider to ensure effective use of the Internet include:

- Some students and lecturers may be unwilling or anxious about adopting new learning styles. It is crucial to provide education about the role of the Internet in education.
- Despite understanding the educational reasons for using the Internet some students will continue to resist and/or will perform less well. Programme evaluations should thus investigate both attitudinal (e.g. preferred learning style) and practical factors (e.g. experience with computers) responsible.
- It is a myth that Web-based materials are less resource intensive to run. Rather, the nature of the educational process changes [46].
- Thought needs to be given to the extent to which the course requires changes when the Internet is introduced. Online learning might reduce the number of lectures or practical sessions, but new tutorials to introduce students to the package or discuss students' learning experiences may be required [8].
- Students lacking basic computing skills should be taught such skills in a non-threatening environment. Anxiety about using computers often explains resistance to IT.
- Student access to online resources must be considered. Ensure that socially disadvantaged students have equal access to the Internet and that resources are available in clinical settings [47].
- Remember that problems occur. Strategies are needed for dealing with contingencies such as Web servers being down at crucial times, or students forgetting login passwords.
- The potential for technology to keep material contemporary will not be realized unless online updating occurs!
- The quality of information on the Internet varies widely and thus has as much potential to misinform students as to inform them. Systematic assessment of sites recommended to students can guard against this [48].
- Students may experience anxiety in dealing with the vast quantity of information on the Internet and using their time effectively when searching. Practical tutorials could address these problems.

- Using the Internet, students are likely to encounter information contrary to local practice or opinion. Mechanisms for dealing with this should be considered.
- Many universities are still struggling with issues of intellectual property and copyright (p. 38) as they relate to online education. Academics involved in such programs should consider these issues and monitor developments.

Resources to support online course development and learning

Web learning environments connect educators, students, and learning resources using the Internet. Software to design such Web environments contain standard features such as facilities to set up discussion groups and e-mail for students, to develop multiple-choice self-assessment questions with immediate feedback and hyperlinks to further relevant information, and to monitor students' progress. Within these learning environments it is also possible to import learning objects such as a simulation application, along with a host of multimedia including video streaming, images, animation, and sound effects. Example software solutions are:

WebCT:
http://www.webct.com/

Lotus Learning Space:
http://www.lotus.com/home.nsf/welcome/learnspace/

Blackboard:
http://www.blackboard.com/

MedEd is a mailing list where medical educators around the world discuss the development and use of IT in education. This forum allows a broad-based and swift exchange of ideas on courseware, authoring tools, and evaluation criteria and methods, and other infrastructure and technical issues:

http://www.aamc.org/meded/

The World Federation for Medical Education (WFME) has produced general guidelines for using computers and the Internet in medical education [49]. The *British Medical Journal* student Web site links to a broad range of medical education sites for medical students:

http://www.studentbmj.com/

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4.2 Continuing professional development

Peter Toon

This chapter addresses the impact of the Internet on two conceptually complex aspects of learning, both undergoing rapid change and confusing in nomenclature: learning for and in clinical practice, and learning at a distance. Just as obtaining information from the Internet effectively requires a well-defined search question, so it is necessary to understand these educational issues to gain maximum benefit from the considerable learning opportunities that the Internet offers.

The examples used are just a few of those available, chosen to illustrate the range of options available rather than as recommendations. A list of educational Web sites would be out of date before it was published. A well-designed query and a good search engine are the best answer for those who wish to discover what is currently available to meet their needs.

Learning for and in practice

Learning by doctors after basic and postgraduate education and training is traditionally referred to as continuing medical education (CME). Recently the term continuing professional development (CPD) has become popular [1]. Like life-long learning, another fashionable term, this shifts the emphasis, acknowledging that teaching does not always imply learning. It also acknowledges that even learning, at least in its narrower senses, does not adequately describe the continuing growth that characterizes a successful and satisfying career.

The various terms, however, conceal rather than clarify different views about what this involves. For some, it is largely a matter of 'keeping up to date' in a rapidly changing scientific world [2]. Although this is important, none of us knows more than a fraction of existing knowledge, and can exercise only a small proportion of our potential skills. Learning to know and do things familiar to others but new to us benefits our patients and ourselves greatly. Being reminded of what we already know and maintaining enthusiasm and motivation are also important elements in continuing development.

Educationalists often divide learning into knowledge, skills, and attitudes. Like undergraduate learning (see Chapter 4.1), postgraduate education has often taken Mr Gradgrind's view that 'what I want is, Facts. Teach these boys and girls nothing but Facts. Facts alone are wanted in life' [3]. Education is filling learners with facts, a view often referred to as 'instructivism'. Reading or attending lectures from experts [4] is the traditional method of conveying this information, and is probably still the most widely used [5].

Sadly, research has demonstrated that these methods have little impact on practice [6]. Moreover in recent years doctors have become increasingly aware that, though a sound knowledge base is essential to their work, skills of communication, clinical diagnosis, and judgement, operative skills, and problem solving are the heart of their expertise. As the Internet makes medical information more easily accessible to everyone this will increasingly be true. Similarly, as patients become more and more informed consumers of medical services rather than passive recipients of what is offered, and their expectations rise, the development of the personal qualities, attitudes, or virtues needed to face the challenges of clinical practice become increasingly important.

Psychological and educational research [7] suggests that learning is better understood not as accumulating facts but as forming links and building new understandings, which cover knowledge, skills, and attitudes—the 'constructivist' view. This view of learning has led to a range of new approaches, with more emphasis on interaction between learners and new material, between fellow students, particularly in small groups, and between the existing knowledge and experience of learners and new problems and ideas. Terms such as active learning, self-directed learning, and problem-based learning are used to describe some of these, whilst practice-based learning and learning sets are examples of their application to general practice.

All doctors in the United Kingdom face compulsory revalidation by the General Medical Council, and those working in the National Health Service (NHS) possibly also a regular appraisal:

http://www.gmc-uk.org/revalidation/

In other countries similar procedures already exist or are imminently likely. Details of these procedures are not yet clear, but it is certain that they will require doctors to organize and document their education, whatever it is called, whatever it covers, and however it is done, more formally and probably to demonstrate its relevance to their work [8]. One advantage of computer-based learning is that it can automatically record learning activities undertaken, how long is spent on them, and deliver and document formative and summative assessments.

Learning at a distance

The Internet can be used merely as a search tool for conventional postgraduate courses, and there are a number of convenient portals. For example:

ukpractice:
http://www.ukpractice.net/

Online CME sites:
http://www.netcantina.com/bernardsklar/cmelist.html

The Internet is also a medium for learning in its own right. Learning arrangements where teacher and learner are separated in time and place originated in the correspondence course, when the post was the main means of distant communication. More recently telephone, television, radio, and video have enriched the exchange of written text. Computers transform distance learning by adding a range of new educational methods. Even stand-alone computers, using programmes loaded from floppy discs or CD-ROM, can provide opportunities for interaction with material impossible or very clumsy with paper-based media (e.g. the 'Update for GPs' series [9]). The Internet is a convenient way of distributing these computer-based learning materials, although it has its technical limitations, particularly in bandwidth (p. 16). For example moving pictures, valuable for many clinical topics, are not really feasible until broadband Internet connections are more widespread, and so a number of computer-based learning packs are still distributed on CD-ROM rather than via the Internet (e.g. the APOLLO programme [10]). A unique facility of the Internet, however, is computer conferencing. This can transform distance learning from a solitary to a group activity, which many find both enhances learning and supports motivation (see Chapter 2.3).

So powerful are the methods utilized in second and third generation distance learning that they are used not only for studying at a distance but when learners are on the same site; the term 'open' rather than 'distance' learning is therefore now often used.

The Internet and face-to-face learning methods

In general the great advantage of Internet learning is that it is convenient, since it can be done at a time and place chosen by the learner. Internet access costs are falling, and are usually less than travel costs to face-to-face courses. There are Internet parallels for most face-to-face learning methods, summarized in Table 1 with their advantages and disadvantages, and discussed in this section.

There is a vast amount of CME material on the Internet. Much of it is open access, while for other courses it is necessary to register and sometimes to pay a fee. As with other aspects of the Internet, the ease of online publication means that quantity does not equate with quality (see Chapter 7.3). Unlike much Web material, most if not all CME sites are factually accurate, since CME is just not sexy enough to attract the wilder fringes of online lunacy, but the usual proviso with any form of medical education, that the interests of drug companies need to be watched carefully, certainly applies. But standards of presentation and educational quality vary enormously, from excellent to embarrassingly bad. The market has not settled down, and while there is much bad free material, some of it is excellent, and paying a fee does not necessarily guarantee the product will be better.

Table 1 Internet parallels for face-to-face learning methods

Face-to-face options	Internet equivalent	Internet advantages	Internet disadvantages
Reading current journals	Electronic journals	Wide variety; easily available	Portability; access
Searching old journals to answer queries	Searching electronic journals	Easily available; easily searchable; no need for storage or cataloguing	Requires skills and equipment; may be charges (cf. browsing library copies of journals)
Lectures	Internet information sites	Notes readily transcribed; flexibility in timing, cheaper than travelling, less time consuming	Requires skills and equipment; transcripts not always available online; lose charisma of a good speaker
Informal group contacts and formal group work	Virtual groups and mailing lists	Work with people from a variety of locations and backgrounds; no need to travel	Face-to-face groups with local knowledge can work closely to retain focus and implement ideas

Using the Internet on your own

Reading journals is one of the oldest approaches to CME. An increasing number of journals are now available online (see Chapter 7.1). For the subscriber a learned journal is both a newspaper, letting them know what is happening in their field, and also an archive, whose back numbers can be searched to answer specific queries. As a newspaper, the e-journal continues to have drawbacks compared with paper versions. Although access and convenience are improving with laptops and mobile phones, the electronic journal is still less portable and rapidly accessible than the paper version which can be read in odd moments at airports, on trains, or by the fireside. Many people find reading material on-screen less comfortable than on paper.

As a searchable archive, however, the reverse is true. There is no longer any need for studies to be lined with back numbers of journals, or libraries to be visited to find them. A MEDLINE (Chapter 6.1) or keyword search can turn up a paper in minutes that could take hours to find by hand. Textbooks and databases, as well as guidelines and policy statements, are all easily available. Although CPD is more than keeping up to date with new knowledge, it remains true that medicine is changing rapidly and a tremendous amount of relevant new information is constantly becoming available. One way in which the Internet can potentially help is by improving access to this information (as described in Chapter 6.2) so that it can easily be retrieved when needed. Effort can then be more profitably directed to learning skills (including how to find facts) rather than to memorizing facts.

Lectures are an even older educational tool than journals, and easily adapted to the Internet. A surprisingly large number of sites offer merely the text of a lecture, in print or sound, perhaps accompanied by slides, preceded by learning objectives and followed by a multiple choice questionnaire that has to be submitted in order to obtain CME credits (Postgraduate Educational Allowance or PGEA hours for UK GPs). Examples can be found via the Medscape CME Center:

http://www.medscape.com/Home/CMEcenter/CMECenter.html

While the need to complete a questionnaire encourages attention in a way not required at a lecture, this offers little more than reading a journal (which may do the same e.g. *Update*), and lacks the social elements, opportunity for questions, and charisma of the traditional lecture [11].

Others sites offer active or problem-based learning that is both instructive and entertaining. Case-based learning where the range of options is limited adapts well to the Internet. For example, the Faces of Domestic Violence site uses such an approach skilfully:

http://www.netcantina.com/terri_as_alison/index.shtml

Well-designed exercises that stimulate reflection or link learning to previous experience also work well (e.g. the EPIC training package for primary care tutors of medical students at the University of North Carolina). Links to the learner's own practice can also be encouraged (e.g. the 'Diabetes and Primary Care' PGEA modules).

Expert Preceptor's Interactive Curriculum (EPIC):
http://www.med.unc.edu/cgi-bin/fipse/

'Diabetes and Primary Care' PGEA modules:
http://ds.dial.pipex.com/sbcomm/dpcpgea.html

In contrast, despite some brave attempts (such as the Virtual Frog Dissection Kit), the Internet offers little for those wishing to learn practical skills such as clinical examination or surgery, although virtual reality may make this possible in the future. Nor is online learning of interpersonal skills such as history taking particularly successful. The Interactive Patient gamely tries to give a history in response to questions from the learner, but the software is not sophisticated enough to deal with the myriad different ways in which one can ask clinical questions: 'I'm sorry I do not understand the question' is too often the reply.

Virtual Frog Dissection Kit (Lawrence Berkeley National Laboratory):
http://www-itg.lbl.gov/vfrog/dissect.html

Interactive Patient (Marshall University School of Medicine):
http://musom.marshall.edu/

The Internet in company

Most doctors would agree that sharing ideas with fellow professionals is an important aspect of CPD which helps maintain enthusiasm. Successful face-to-face events (conferences, workshops, even lunchtime meetings) may achieve as much through these informal contacts as in the formal programme, though it is diverse and serendipitous and thus hard to evaluate and document.

For many doctors this need is met wholly or partly through the Internet. This may be as simple as exchanging e-mail with distant colleagues with similar interests, through formal mailing lists run by special interest groups (e.g. GP-UK) to formal online conferences.

GP-UK:
http://www.jiscmail.ac.uk/lists/gp-uk.html

While the synchronous ('real time', p. 78) conferences available via chat rooms are great fun and their immediacy is initially attractive, most people have not found them particularly conducive to serious discussion. This may of course change, as bandwidth improves and videoconferencing becomes more routine. At present, however, most serious discussions over the Internet are asynchronous (p. 78). A contributor logs on, reads the messages in the discussion, may post a reply, and then logs off until hours or days later when he or she goes back online to find out how the debate has progressed.

Asynchronous online interaction resembles small group work, and can similarly be used for exchange of information and opinion, problem solving, debate, and support. However, the slow motion intermittent discussion (sometimes referred to as 'slow throwing') based on text alone, without non-verbal cues, has qualities which make the experience different. The absence of a need for instant response means that contributors can plan their comments at leisure, which can make for a more reflective discussion—though of course it does not always do so.

Most asynchronous conferences are informal discussions or more formal debates, rather than the structured learning activity of problem-based or other types of learning groups. There are, however, an increasing number of online courses that include online interaction with fellow students and tutors, alone or combined with other elements of computer-based learning. The MSc in Primary Health Care at University College London, for example, is entirely Web-based (Fig. 1), and its core is a series of 'virtual seminars' in which students discuss papers they have written or work on tasks together in a structured learning environment with clear objectives:
http://www.ucl.ac.uk/primcare-popsci/msc/

Some people fear that Internet group work will miss the interpersonal sparks and non-verbal insights that characterize group learning in a face-to-face environment. Those who have taken part in such groups do not usually share these fears, or find that potential difficulties can be overcome.

Virtual groups are discussed further in Chapter 2.3.

The teachers' perspective

Teachers thinking of working through the Internet should count the cost. Putting lectures on the Web and adding a few multiple choice questions

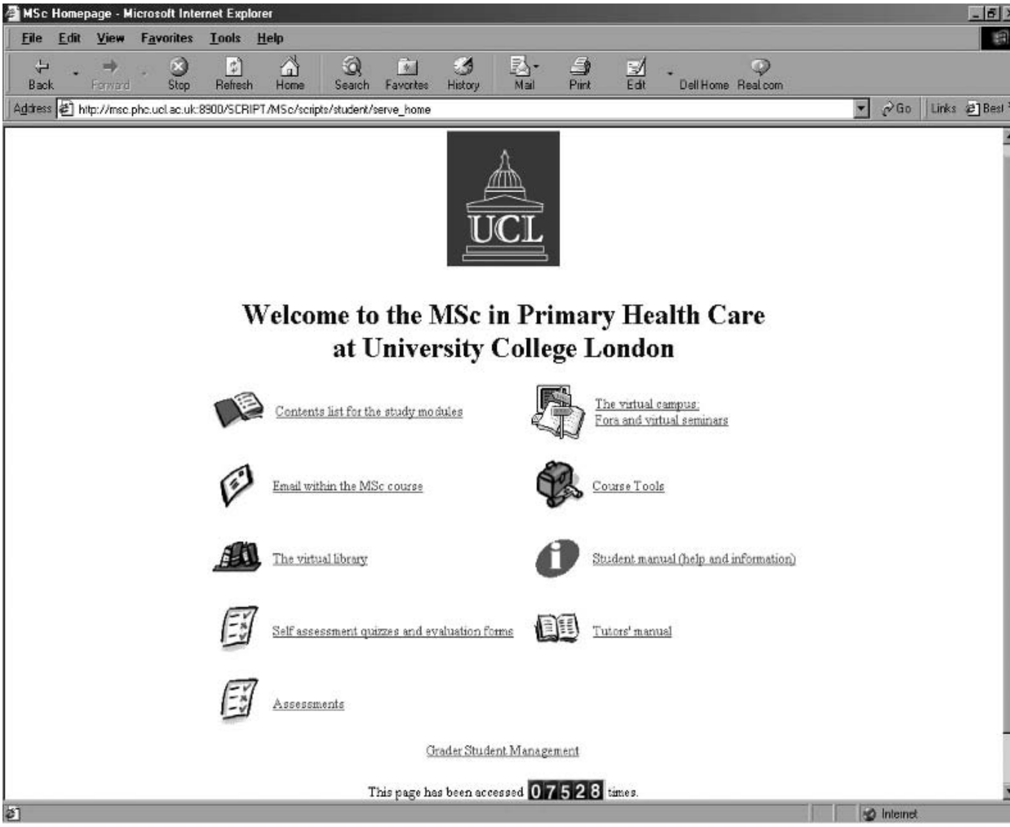

Fig. 1 University College London offer a Web-based MSc in Primary Health Care.

costs little and achieves little. Devising attractive and effective interactive educational materials, on the other hand, is expensive and time consuming, particularly if they are self-sufficient, providing computerized feedback to the learner in response to his or her decisions. It can take between 50 and 100 hours to devise 1 hour of such material [12], and requires design and technical support as well as educational expertise.

Providing 'e-tivities' (electronic activities) in which learners incorporate new knowledge or practise skills by linking them to their real professional life, or setting up and moderating an online group, is less time consuming, though it does require other skills [13].

The future

The Internet is no more likely to replace the various forms of face-to-face learning than the printing press led the lecture to be replaced by the library. But it offers an extra dimension to learning that would be foolish to ignore. Like other methods it can be used well or badly, and activities need to be selected with care. A checklist for assessing Internet-based CPD resources is given in Box 1.

Box 1 Checklist for assessing Internet-based CPD resources

- Does the resource make creative use of the Internet?
- Does the resource use the Internet as an aid to learning, or just as decoration?
- Does the resource have clear objectives?
- Is the material relevant to my needs and those of my patients?
- Does the Internet offer added value or convenience compared with face-to-face alternatives?
- Will the resource be fun to use?

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5 Using the Internet for patient education

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Information for patients

- More consumers are going online and numbers are rising all the time; health information is commonly sought.
- Consumer health information comes from a wide variety of sources including government-sponsored institutions and healthcare providers; information from authoritative organizations and societies; universities, academics, and medical group Web sites; information from commercial concerns; and patient self-support and mutual support groups.
- Strategies to cope with Internet printouts brought to the consultation include drawing up ground rules for what can be brought to the consultation; discussing quality issues with the patient; requesting an advance preview of what the patient is going to bring; using the Internet yourself to dovetail with what the patient has found; and letting the patient do *your* research.
- In the future patients and consumers will be better informed, will have more information about their healthcare providers, and may even select their healthcare providers based on Internet databases.
- Healthcare can be viewed as a business transaction that will be revolutionized by Internet technologies.

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5.1 Information for patients

Harry Brown

As doctors and health professionals we tend to focus on the Internet resources that interest us. It is easy to forget, however, that there is a massive volume of information that is designed for use by the health-care consumer. There are varying and sometimes contradictory statistics about the use of the Internet for health information. One survey suggested that more than half the people in America with online access use the Internet for medical or health interests [1].

Without doubt accessing online medical and health information will continue to be a growing phenomenon and will form an essential part of self-healthcare. Even now, it is not uncommon for patients to volunteer that they have discovered additional information about their condition or treatment by using the Internet.

It is not really surprising that the general public have taken to the Internet in droves. The mass of information that is available is mostly free and easily accessible, as well as potentially very up to date. Mailing lists and newsgroups are an ideal place for mutual support and sources of invaluable help. Of course there are downsides to this, principally that the barrier to publication of online material is a lot lower than that for traditional printed media. Any person with a minimal amount of technical knowledge and at minimal cost can produce a flashy and impressive Web site quickly—but with little or no accountability (see Chapter 7.3).

Online content can vary from the dubious to the outrageous and dangerous as well as being commercially biased. For examples of such material see the excellent 'Quackwatch' Web site. Be prepared for a fair amount of scrolling down a long list of hypertext links but it is a fascinating and illuminating offering:

http://www.quackwatch.com/

At the opposite end of the spectrum is the classy, well-written, high-quality material. The problem is of course that many patients (and health professionals as well) may have difficulty in differentiating the good from the bad. Against this background, patients may seek online information and advice for a variety of reasons (see Box 1).

Box 1 Why do patients seek online information and advice?

- A second opinion.
- More time to interrogate the resource.
- A wide variety of resources available.
- Dissatisfaction with their traditional healthcare provider.
- To share experiences and mutual support.
- Convenient to the user (the Internet is available 24 hours a day, 7 days a week).
- Privacy, especially when seeking information about embarrassing issues.

Sources of online information

There is a bewildering array of resources that a patient may call upon and they vary from traditional providers like the UK National Health Service (NHS) who have established an online service, to one individual's Web offering—often describing a personal experience with illness. They all have a unique contribution to make to online healthcare and together make up the rich variety of online resources.

Government-sponsored institutions and healthcare providers

These represent some of the major players in online consumer healthcare resources. They are usually mainstream providers of healthcare and/or government funded. Being big in terms of the size of a Web site, the money behind it, or the organization it represents does not necessarily mean it will be an outstanding site. One significant advantage of the Internet is that a site run by a small group or even an individual can have as a big an impact as that of a major player.

The NHS Direct Online Web site is government funded and the product of the largest healthcare provider in the United Kingdom (i.e. the NHS). NHS Direct Online (Fig. 1) complements the nationally available telephone helpline. For further information see:

http://www.nhsdirect.nhs.uk/

Across the Atlantic is the equally impressive HealthFinder Web 'gateway', which likewise seeks to direct patients toward some excellent consumer information sources:

http://www.healthfinder.gov/

Also from the United States, MEDLINE Plus deserves special mention. This site is produced by the National Library of Medicine and is aimed at

Fig. 1 NHS Direct Online: an online health information resource on the Internet.

both the patient and the health professional. It provides links to some superb resources such as the MEDLINE bibliographic database (see Chapter 6.1) and an excellent array of facilities such as drug information and dictionaries:

http://medlineplus.gov/

Such resources are an ideal starting point to recommend to patients should they seek your advice about finding further health or medical information on the Internet.

Information from authoritative organizations and societies

Well-known organizations or societies with a national or regional role can produce good quality material that is timely and relevant to the consumer.

These organizations have always existed but have often had difficulty in reaching their target audience and providing them with the material and information that they need.

Take, for example, diabetes mellitus, a condition that involves the patient working in partnership with their health professionals. Equally, the patient requires information, sometimes customized, about how to manage their condition. Take, for example, national organizations with an online presence that cover the United Kingdom, United States, and Canada. In the UK the Web site run by Diabetes UK (formerly known as the British Diabetic Association) includes some excellent information about managing diabetes:

http://www.diabetes.org.uk/

In the United States the American Diabetes Association provides a good range of material. Although the site itself contains good patient-orientated information, if consumers are not satisfied with what is on offer there they can browse the excellent section on links to other sites:

http://www.diabetes.org/

The Canadian Diabetes Association Web site is similarly patient-orientated with a well-designed patient information section:

http://www.diabetes.ca/

Although these sites have a specific national audience they can be accessed by anyone from anywhere. They share a number of common positive aspects:

- They are free to use.
- They require no registration (although useful to the organization, this can put off some users).
- They contain material relevant to a consumer's needs.
- They are easy to find from standard Internet search engines (see Chapter 6.2).
- The quality of content is trustworthy since they come from recognized groups.

University, academic, and medical group Web sites

Many health professionals and academics generate a lot of material that until recently would have a limited audience as it was expensive to publish and distribute. Since many of these documents are produced electronically anyway, it is quite a simple task to put them on the Web for reading and downloading. Sometimes this material has an intended readership, for example, a student or GP population, or patients attending a particular hospital department. However, as this is placed on public Web sites and is easily indexed by the standard search engines, it is retrievable by a global audience.

Examples of general practice Web sites:

http://www.internet-gp.com/gp.htm

Sometimes these medical and academic individuals may engage in a one-to-one contact with a patient and this can provide the patient with an informed second opinion. Such e-mail exchange can be a useful service in its own right although concerns over liability for such advice have yet to be fully resolved (see Chapter 2.2).

Information from commercial concerns

It is interesting that the Internet's history is firmly steeped within a military and later on an academic background. It was commercial interest in the Internet, however, that saw it jump from a medium with a select audience to an everyday communications and information retrieval tool. The Internet and the Web in particular is bulging with sites from commercial organizations seeking to attract consumers looking for relevant health information. The word 'commercial' is used rather loosely though it is fair to say that somewhere along the route, many site owners are keen to make money in some shape or form. Many don't do it by directly selling information or services to patients though there are plenty that do (see Box 2).

Box 2 How do commercial sites plan to make money?

- Some have ideas of attracting healthcare consumers to look at their content and generating revenue using online advertising. This is a similar business model to what we see on commercial television and radio.
- Others are out to promote their 'bricks and mortar' business.
- Pay-per-view (usually with credit card details).
- Generate a high levels of hits (i.e. become an established 'portal' site with a high number of users) and then sell the Web site on.
- Other business models are less clear.

Commercially sponsored healthcare information sites may in some cases be identified from their domain name (e.g. those ending '.co.uk'), although commercial involvement may not be obvious—or even acknowledged.

Self-diagnosis and management tools

There are plenty of patient-orientated clinical tools to help in diagnosis, disease management, or for just plain fun. They are more interactive than just passively transferring data, and as the Internet develops they will utilize multimedia capabilities such as video and sound. Most sites carry (or should carry) disclaimers that these clinical tools do not replace traditional forms of clinical care but act as a supplement or merely have educational value. Clinical tools are thus:

- educational
- of potential assistance to a consultation
- fun
- not to be taken too seriously
- not be used in isolation of the clinical issues.

For example, if want to find out how long you could live for, try the longevity calculator at:

http://www.northwesternmutual.com/games/longevity/

Work out your risk of heart disease at:

http://www.usnews.com/usnews/nycu/health/sfheart.htm

Work out when your baby is due at:

http://www.intmed.mcw.edu/clincalc/pregnancy.html

Patient self-support and mutual support

The power of the Internet has allowed patients to come together, support each other and themselves, and share experiences. This rich vein of help can be a vast network of worldwide support using Web sites (often constructed by sufferers themselves), mailing lists, and newsgroups. True, there can be a lot of misinformation discussed in these media. However, there is equally some fantastic online support for patients, carers, family members, and other interested parties. Online support:

- is very popular with patients;
- can add to the sum total of healthcare;
- allows the sharing of experiences to everyone's benefit;
- is more available to the patient and potentially offers more time than a traditional healthcare provider can;
- is likely to grow.

The sharing of patient experiences is something that health professionals often overlook. It can potentially add to the healthcare process by possibly producing a more informed patient. A superb example of what this involves was the case of a young librarian diagnosed with lung cancer, published in the *British Medical Journal* [2]. Using a mailing list, she received support specializing in her problem. The process was so beneficial that she was inspired to produce her own Web site to help patients in a similar predicament to herself:

http://www.lungcanceronline.org/

It is this type of patient-led service that has turbocharged the growth of online healthcare.

Patients and their printouts

Without doubt the spectacular growth of the Internet, and in particular online health information, will generate a more knowledgeable, informed, and questioning patient. It is quite possible that they could be an expert in their own condition simply because they have a vested interest. A doctor must be knowledgeable about many diverse conditions and so may be fazed by the newly empowered health consumer who is an expert in their own disorder and does not have to learn about other conditions. Even worse (from the point of view of many doctors), the patient may bring to the consultation a mountain of printouts from Internet sources—a

Box 3 How do I manage Internet Printout Syndrome?

A knowledgeable patient encourages the doctor to become more versed in their condition. In turn, the doctor should be able to assess what is good quality information and what is poor. If the number or presence of printouts troubles the doctor then ground rules should be laid about what can and what cannot be brought to the consultation. Online research by the patient should encourage the doctor to also venture online and confirm or refute what the patient has found. Finally, ask the patient to do some research for the doctor and either e-mail it or return with a few selected printouts to a further consultation. Patient and doctor partnerships are becoming fashionable and the Internet will help to bridge the large knowledge gap between consumers and their healthcare providers.

The General Practitioners Committee of the British Medical Association produced an excellent tip sheet, which helps both patients and their doctors [4]. This simple listing gives practical advice on how to assess and evaluate information obtained from online sources. This could be used as a tool to manage the Internet Printout Syndrome.

condition that has become known as 'Internet Printout Syndrome' [3]. In fact, doctors need not worry about this new breed of patient but rather view such instances as an opportunity to explore and develop the doctor–patient relationship (see Box 3).

So will the Internet mean the end of the consultation as we know it? 'Probably not' is the simple answer. The growth of the Internet has allowed the liberation of information relevant to both consumers and carers via worldwide distribution. Informed doctors and patients will hopefully lead to better outcomes and health professionals will have to adapt and become guides and assessors of online information.

Even in this enlightened and electronic age, the Internet still has not become the number one source for reliable information. A survey of Californian healthcare users revealed that doctors and traditional healthcare organizations are still highly regarded and remain the most reliable provider of health-related information [5].

Information for patients about doctors

Empowered consumers may start to check out their own doctor or even select their own doctor, via the Internet. Databases are available which can provide such data and supply other background information. Rating doctors is far from easy but public information is available and the Internet is the obvious place to publish it [6]. Soon patients will be able to access their electronic medical records, organize their prescriptions, or select and communicate with their doctor—all online.

The information revolution will impact on the way healthcare is managed. In the same way that commercial organizations have had to rethink the way they work because of the Internet, the practice of healthcare will become more transparent to patients. The liberation of medical and clinical information will accompany the rise of the more discerning consumer.

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6 Using the Internet for research

Accessing MEDLINE

- Easy and efficient access to the clinical journal literature is vital to the process of providing evidence-based healthcare.
- MEDLINE, produced by the US National Library of Medicine (NLM), is the largest and best-known database indexing the clinical journal literature and can be searched for free via the Internet.
- MEDLINE is a highly structured database which, with a basic understanding of the underlying structure, makes for an extremely powerful retrieval tool.
- A MEDLINE search will involve identifying concepts, devising and running a search strategy, and often saving search results.
- The NLM PubMed service offers a user-friendly interface, which assists in each of these steps as well as providing a number of other useful search facilities.
- Tried and tested search strategies are becoming increasingly important as part of evidence-based research. Some search services (e.g. PubMed) are now offering such strategies as part of their main search interface.

Searching the medical Web

- Advantages of retrieving information via the Web include its simple interface; currency of content; breadth of online resources; cost-effectiveness; and malleability of content to individual requirements.
- Medically focused indices and search engines have been developed. Manual indices employ people to select and catalogue Web sites producing directories, whereas automated search engines use computer programs to generate searchable indices.
- Manual directories are generally better at locating whole Web sites relating to a particular topic, whereas computer-generated indices are generally better at locating individual Web pages or more specific information.
- Directory-based indices have evolved into primary Web access points ('portals'). All include search engines allowing keyword querying of the directory.
- Human-readable sites that are 'directories of directories' are termed 'meta-directories'. Both directories and automated search engines may use 'metadata'—data about data that describe an individual resource in a machine-readable language.

continued

- Challenges to retrieving information via the Web include the lack of built-in document indexing; the nuances of human language; and difficulties in determining resource quality.

Facilitating research

- Researchers can utilize the anonymity of the Internet to conduct qualitative health research using techniques of passive observation, active participation, or interviews and surveys.
- Conducting surveys via the Internet requires an awareness of various methodological issues, selection bias, and technical issues.
- Obtaining informed consent is difficult in some circumstances, but is required when data are collected from research participants through any form of communication, interaction, or intervention, and when observation occurs in a context perceived to be private.
- The Internet can help researchers find information about laboratory or clinical protocols, or about statistical methods and instruments.
- Internet databases of current clinical trials can identify these to both researchers and prospective participants. Furthermore, the Internet can support patient data entry and trial protocol dissemination.
- Electronic 'pre-publication' of preliminary research results and conclusions facilitates an ongoing process of peer review and online collaboration. Automated current awareness services alert researchers to the ultimate publication of new work.

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6.1 Accessing MEDLINE

Jane Rowlands

Why access the clinical journal literature?

Easy and efficient access to the clinical journal literature is a vital ingredient in the process of providing evidence-based healthcare. Evidence-based care relies upon systematically finding, appraising, and using contemporary research findings as the basis for clinical decision-making [1]. Databases such as MEDLINE play an important role in indexing the literature upon which evidence-based research and practice might be based. Other Internet resources supporting evidence-based practice were considered in Chapter 3.1. The increasing adoption of the principles of evidence-based medicine has seen particular emphasis placed on using these sources to locate systematic reviews and studies incorporating sound methodological design, such as randomized controlled trials. Optimal search strategies (often referred to as filters) for retrieving such high-quality evidence are currently being developed, tested, and made available to end-users. Data suggest that rapid and effective access to biomedical research can be crucial to sound patient care and favourably influences patient outcomes [2–5].

What is MEDLINE?

MEDLINE is the largest and best-known database indexing the clinical journal literature. Produced by the US National Library of Medicine (NLM), MEDLINE incorporates the printed *Index Medicus*, *Index to Dental Literature*, and the *International Nursing Index*. It has a broad subject coverage including the medical and surgical specialties, pre-clinical sciences, dentistry, nursing, veterinary medicine, and healthcare administration. MEDLINE currently contains around 11 million records and indexes around 4 500 different journal titles taken from over 70 countries. At least 70% of MEDLINE entries include abstracts.

NLM:
http://www.nlm.nih.gov/

MEDLINE is a bibliographic database. It does not contain the full text of articles. Commercial database providers such as OVID and Silverplatter produce and license a range of full-text databases which link with their own copies of MEDLINE. Free full-text content for a limited number of journals can be viewed at the NLM's PubMed Central site.

OVID:
http://www.ovid.com/

Silverplatter:
http://www.silverplatter.com/

PubMed Central:
http://www.pubmedcentral.nih.gov/

MEDLINE is a highly structured database which, with a basic understanding of the underlying structure, makes for an extremely powerful retrieval tool.

Journal articles included in MEDLINE are indexed using over 17 500 standardized thesaurus terms. These are called Medical Subject Headings, abbreviated to MeSH. Using MeSH terms to conduct a search helps ensure all relevant citations are retrieved, whereas using your own choice of words or terms may retrieve a more limited set of results. For instance, problems may arise from the use of singulars and plurals, the differences between British and American spellings, or the use of synonyms by different authors.

As a further aid to retrieval, indexers mark MeSH terms if the subject they describe is a major concern of the article being indexed. In this case the term is referred to as being 'majored'. MeSH terms may also be combined with sub-headings. There are over 80 sub-headings that describe particular aspects of, or particular ways of looking at, the subject concerned.

MeSH terms are divided into 15 main groups. Within these groups MeSH terms are arranged hierarchically, with broad topics branching into progressively narrower topics. This is often referred to as the MeSH tree structure (see Box 1).

This hierarchical structure can be used in order to 'explode' a search for a fairly broad topic such as 'lung diseases' to include all related and more specific sub-topics. This is a very powerful search feature but one that needs to be applied carefully. MEDLINE indexers are instructed to index using the most specific terms possible when dealing with individual articles.

Box 1 The MeSH tree

As an example, the broad term 'lung diseases' branches into many narrower topics including lung diseases, fungal. This in turn branches into the even narrower topics aspergillosis, allergic bronchopulmonary and pneumonia, pneumocystis carinii. In schematic 'tree' form:

lung diseases
- lung diseases, fungal
  - aspergillosis, allergic bronchopulmonary
  - pneumonia, pneumocystis carinii

When searching it is best to use the most specific word or phrase available as a MeSH heading that describes the subject in which you are interested. Searching using a broad MeSH term will find only very general articles on that topic. Exploding a broad MeSH term may retrieve articles on very specific but related topics that are not relevant. Explode a broad MeSH term if you are sure that you wish to retrieve all, or most of, the narrower terms that fall under it in the MeSH tree. You will only retrieve narrower, related terms if the broader MeSH term is exploded.

MEDLINE via the Internet

In addition to 'traditional' access via subscription-based CD-ROM, MEDLINE can be accessed via the Internet. Sometimes online access is provided by subscription. Subscription-based online access is offered by a number of companies such as OVID and Silverplatter (as above). In these cases the subscription is also likely to include access to a wide range of other databases (some full-text) that may be searched in combination with MEDLINE.

National and regional organizations such as the British Medical Association have purchased their own copies of MEDLINE, and additional databases, from commercial producers such as OVID and Silverplatter. These are hosted and supported via the Web, free of charge, to members and/or staff.

BMA MEDLINE Plus:
http://ovid.bma.org.uk/

Since the NLM has made the MEDLINE data freely available it has been possible to access the database for free via the Web from many different sources. Among these is the NLM's own popular PubMed service:

http://www.ncbi.nlm.nih.gov/entrez/

Web sites including Organizing Medical Networked Information (OMNI) and Medical Matrix have compiled online guides to free sources of access to MEDLINE via the Web and offer some means of comparison between them. Using MEDLINE via the Internet has a number of advantages and disadvantages (see Box 2).

OMNI:
http://omni.ac.uk/medline/

Medical Matrix:
http://www.medmatrix.org/

Box 2 Advantages and disadvantages of MEDLINE via the Internet

Advantages

- It is up to date.
- It requires less investment in hardware (e.g. multiple CD-ROM drives).
- It does away with reliance on a regular supply of updates on CD-ROM.
- It is available to a wider audience; it can be accessed from a variety of locations (e.g. work, home, library).
- As a 24-hour service, it can be utilized when most convenient.
- Search results can be saved directly on to the user's own computer.

Disadvantages

- It has a non-standard interface (dependent on provider).
- Help from a librarian may not be at hand.
- Searches may be slow due to the high number of users.

Some important points to consider in using any MEDLINE service:

- Does it offer the full MEDLINE database, back to 1966?
- How often is it updated?
- Does the search interface make it easy to take advantage of the MEDLINE indexing features discussed in the previous section?

- Are search filters, to retrieve systematic reviews or randomized controlled trials for example, incorporated as part of the search interface or made available for that particular search interface?

Searching MEDLINE

The best way to illustrate some of the principles of searching MEDLINE is to work through an example. Further guidance is available elsewhere [6–11]. As the interface will vary, check the help screens provided as part of the service you are using for more specific information regarding available search facilities. Any MEDLINE search will involve identifying concepts, devising a search strategy, and saving your results.

Identifying concepts

A first, crucial step with any subject-based query is to break down the original question into individual concepts. Once the concepts are established (there may be just one, or, with a complex query a number of different concepts) the next task is to decide how these might be identified within MEDLINE. This could be done in any of the following ways:

- by using an indexing MeSH term;
- by searching for text in the title or abstract;
- by using a sub-heading;
- by using limits.

Using an indexing MeSH term

An important consideration here is whether or not the concept is best identified using a specific indexing term. You may alternatively need to explode a broader term to include all related topics that fall under it in the MeSH tree as previously described. You need also to bear in mind whether you wish to search for the term selected as a main focus of the articles to be retrieved (e.g. for a very well-researched topic), or whether you wish to pick up all articles indexed with that particular indexing term (e.g. for a less well-researched topic).

The more comprehensive MEDLINE search interfaces (e.g. PubMed) attempt to match your own words or phrases to appropriate indexing terms. Note that PubMed will automatically explode any broad MeSH terms selected. PubMed also offers a MeSH browser facility (see Fig. 1) that allows you to check an alphabetical list of MeSH terms, along with a brief snapshot of where they fit within the overall MeSH hierarchy.

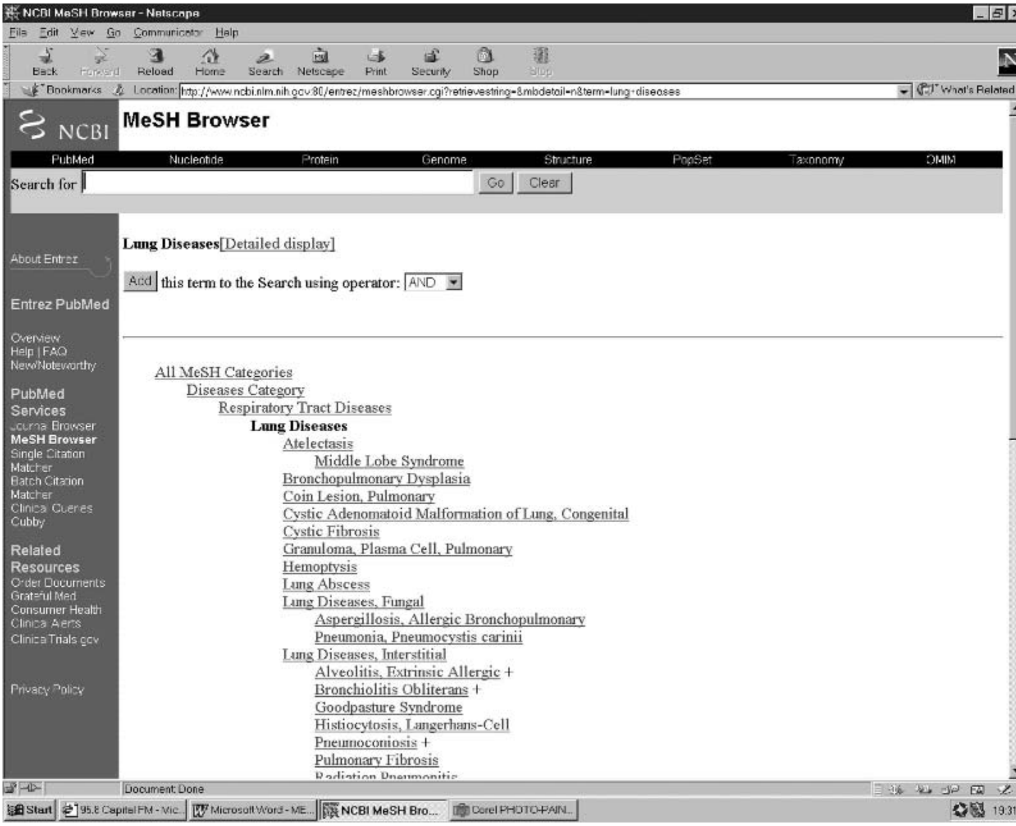

Fig. 1 PubMed's MeSH browser facility.

Searching for text in the title or abstract

This technique is particularly useful when searching for a proper name (e.g. Wellcome), a new topic, buzzword, or phrase. It may be possible (depending upon the MEDLINE search interface you are using) to refine this technique by using a wild card character to search for a word stem (i.e. the first few characters of a word followed by any other characters). For example, searching for the word stem 'operat', plus the relevant wild card character (e.g. '*'), will retrieve articles containing words such as 'operate', 'operates', 'operating', or 'operated'. This process is often referred to as truncation.

Using a sub-heading

Use a sub-heading if one of the 80-plus MEDLINE sub-headings is appropriate to a concept you wish to identify, and if that sub-heading can be applied to the indexing term concerned. For example, it is possible to associate the sub-heading 'adverse effects' with indexing terms that represent individual drugs, again using the PubMed advanced searching option.

Using limits

Limits may be offered by the particular search interface providing your access to MEDLINE. For example, limits to English language articles, articles dealing with human subjects, or particular age groups are often available. Note that if you are working on a complex search query which requires combining search concepts it is good idea to limit your search results at the very end of the process, once sets have been combined as described below.

A search strategy

Once you have decided how you are going to identify the concepts which make up your original search query it is possible to put together a series of search steps (often called a search strategy) to identify those concepts, one at a time. The search steps then need to be brought together (combined) to produce a final result.

The way in which the individual search steps (often called search sets) are combined is itself vital to the overall result. MEDLINE search sets can normally be combined according to the principles of Boolean logic. A small number of standard words/characters (often called operators or Boolean operators) are used to represent possible combinations. Typically, these include AND, OR, and NOT.

And

Combining two or more search sets with 'and' will typically mean that only articles relevant to all the concepts represented by those search sets will be retrieved. In this case the final results (once the sets are combined) is likely to include fewer references than any of the original search sets. For example, combining a search on 'hay fever' with a search on 'asthma' using the operator 'and' will find only articles concerned with both asthma and hay fever.

Or

Combining two or more search sets with 'or' will typically mean that articles relevant to any of the concepts represented by those search sets (or two or more of them) will be retrieved. In this case the final result (once the sets are combined) is likely to include more references than any of the original search sets. For example, combining a search on hay fever with a search on asthma using the operator 'or' will find articles concerned with either asthma or hay fever or both.

Not

Combining two search sets with 'not' will typically mean that items including the concept represented by the second named search set will be removed from the first named search set. In this case the final result (once the sets have been combined) is likely to contain fewer references than the original first named search set. For example, combining a search on hay fever (search set 1) with a search on asthma (search set 2) using the operator 'not' will find articles concerned with hay fever; any articles also concerned with asthma will be eliminated (see Fig. 2).

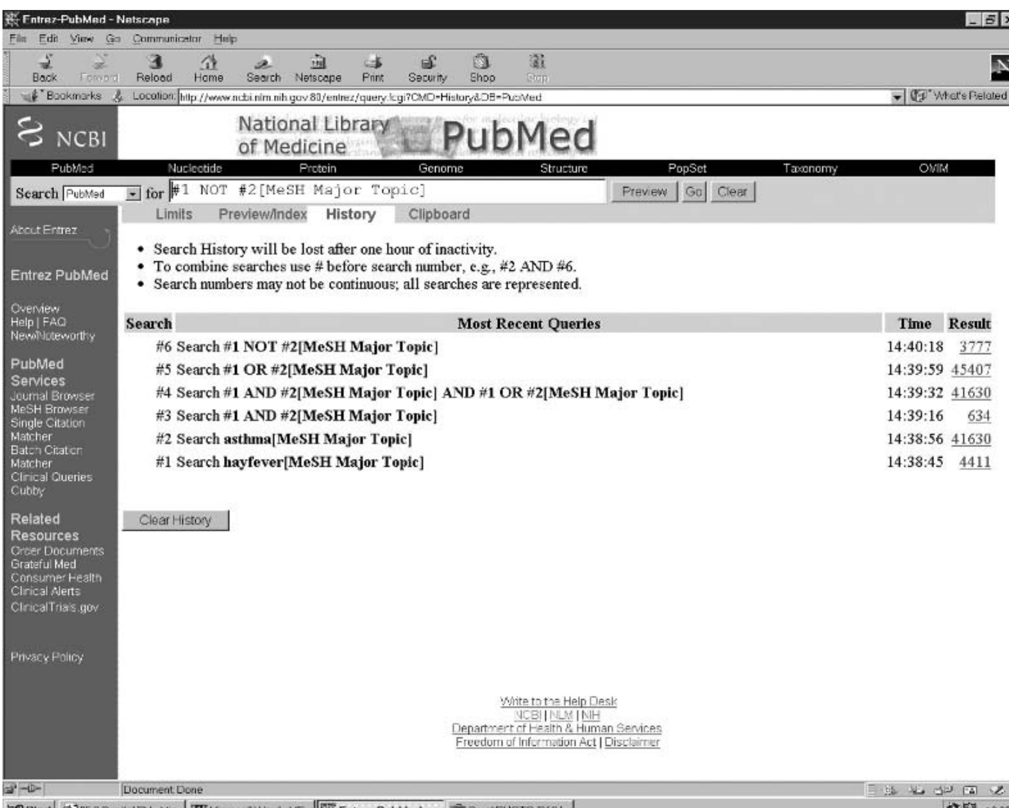

Fig. 2 PubMed allows the combination of search sets.

Box 3 What to do if you retrieve too many or too few articles

Too many articles

- Check, have you used the most specific MeSH terms possible?
- Check, have you exploded a broad MeSH term unnecessarily?
- Apply appropriate sub-headings to the MeSH terms you have chosen.
- Apply further limits to your search results.
- Check, have you used the correct Boolean operator when combining the various aspects of your search.

Too few articles

- Check, have you selected MeSH terms that are too specific? Should you have exploded any of the MeSH terms?
- Check, have you been too restrictive in applying sub-headings or limits to your search results, or by requiring that the MeSH terms you have selected be a major focus of the articles retrieved?
- Check, have you used the correct Boolean operator when combining the various aspects of your search?
- Search for your topic using both MeSH terms and in the text (for example titles, abstracts) of records. It is particularly useful to search the text where your topic does not match an appropriate MeSH term.
- Check the MeSH terms associated with any particularly useful articles. Use these to help locate additional material.

With some complex search queries it may necessary to carry out one or more combinations, using different operators. For example, you might combine searches on asthma (search set 1) and hay fever (search set 2) and inhalers (search set 3) to find references concerning the use of inhalers for asthma or hay fever. Here, it is first necessary to combine search set 1 with search set 2 using the operator 'or' to retrieve articles concerned with either asthma or hay fever and then combine the result with search set 3 using the 'and' operator to give the final result.

Some tips if you retrieve too many or too few articles are given in Box 3.

If you are instead trying to locate details of a partially known item, combine searches looking for information that you have already in the appropriate field (e.g. author name, journal name, year, volume number, or page number) using the 'and' operator. When searching for authors always make sure you know how these are formatted for the particular search interface you are using. The PubMed service has a single citation matcher facility that makes this process very simple indeed (see Fig. 3).

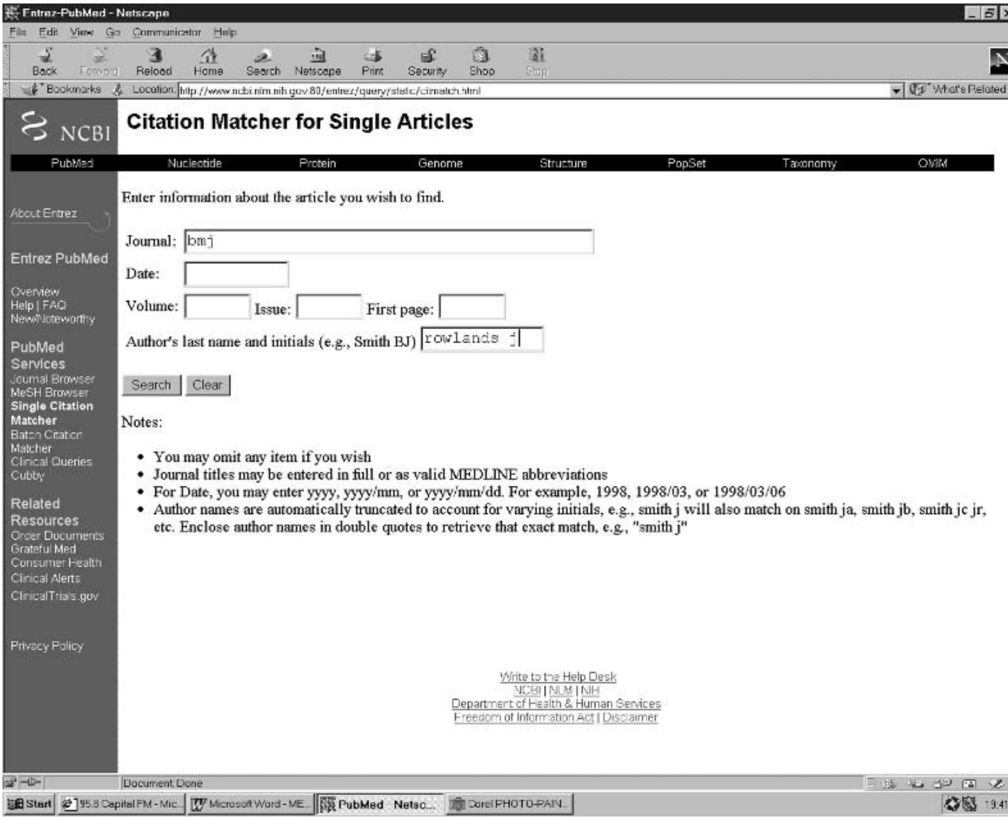

Fig. 3 PubMed's single citation matcher facility.

Saving search results

Once you have your final search results you may then wish to display them on the screen and ultimately save some or all of them to your own computer. Methods for doing this will vary depending upon the particular search interface you are using to access MEDLINE. When using the PubMed service, for example, use the 'go' button to execute your search and then the 'display' button to display them on the screen in the desired format.

To save your search results, again use the 'go' button to execute your search and then the 'save' button to save them to your own computer. Select where you would like the file containing the results to be saved and what you would like the file to be called.

Other PubMed features

We have already noted PubMed's MeSH browser and citation matcher facilities. Other useful facilities provided by this service include:

- **Journal browser:** a means of checking which journals are indexed in MEDLINE and for the official MEDLINE abbreviations for those journals.
- **Clinical queries:** an easy means of using specially developed search filters to retrieve articles relating to the therapy, diagnosis, aetiology, or prognosis for individual conditions.
- **Cubby:** a stored search feature allowing users to store and update searches.

MEDLINE search filters

Tried and tested optimal search strategies are becoming increasingly important to the process of evidence-based research and practice [12–14]. Some services (e.g. PubMed) now offer such strategies as part of their main search interface. Strategies for use with other search interfaces (e.g. OVID and Silverplatter) are being developed and made available via the Web, such as those provided by the University of Hertfordshire:

http://www.herts.ac.uk/lis/subjects/health/ebm.htm#filt

The strategies can be linked with the results of a search on a particular topic to retrieve, for example, just systematic reviews or randomized controlled trials on that topic.

Personal bibliographic software

These products are becoming increasingly familiar to practitioners and researchers alike. Three of the most popular are Reference Manager, ProCite, and EndNote. Further details about these applications are available from the ISI ResearchSoft Web site:

http://www.isiresearchsoft.com/

In brief, the main features of these software programs include the ability to:

- organize references, from a variety of different sources or entered manually, into a database;
- recognize a wide range of reference formats;

- create bibliographies automatically (exported to standard word processing packages) in a choice of reference styles (e.g. 'Vancouver');
- search bibliographic databases on the Internet directly.

It is possible to use a program like EndNote to connect directly to a highly structured database such as MEDLINE via a basic, common interface (the Z39.50 protocol being the best known example). In doing this, please note that where the original host (e.g. PubMed) offers a comprehensive search interface to assist in making the most of the structural features of the database, much of that functionality will be lost. An alternative is to save references to your own computer first and import them into the bibliographic software programme afterwards.

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6.2 Searching the medical Web

Richard Appleyard

Information retrieval on the Web

There are many advantages to retrieving information on the Web. The interface is simple and access is ubiquitous. Information can be constantly updated and is immediately available. There is a continually expanding knowledge base of health information ranging from clinical guidelines to patient education materials. The Web is also a major source of freely accessible, edited information that has been traditionally difficult to find in a timely and cost-effective manner. Many Web information sources are as well defined contextually as their print equivalents, targeting particular types of information user by their demographics and subject area of interest.

Knowledge-based, scientific information can be divided into three categories [1]:

- **Primary:** original research printed in peer-reviewed publications (journals, books, etc.).
- **Secondary:** catalogues and indices of the primary literature.
- **Tertiary:** the rest of published scientific information, including text-books, review articles, desktop reference materials, etc.

Initially there was not much access to the traditional, hard copy published material on the Web as publishers feared that this would negatively impact upon their source of revenue. The Web therefore became a tremendous source of tertiary materials as the traditional barrier to publishing fell away. Alongside this came an increased difficulty in assessing the validity of the information published online (though the same rules apply to the online world as for the print world). Today many primary literature sources are available in this online environment (although not all are freely accessible) and new electronic-only, peer-reviewed journals are now established on the Web (see Chapter 7.1).

The main disadvantage of information retrieval on the Web is that it is difficult to locate information efficiently and effectively (see Table 1). This having been said, it is amazing how the Web can be used to track down information about something you have come across. HTML (p. 36) does not have any indexing built into it, and so consequently a tremendous amount of effort has been expended upon both manual and automated indexing. This effort includes the development of a number of medically focused indices and search engines, paralleling the increasing count of medical databases and other resources now accessible via the Web.

How does one go about searching the Web for medical information? One of the challenges here is the rapid pace of change. As such, this author describes major information retrieval resources that have withstood the test of 'Internet time' or those thought to have the most staying power.

Table 1 Potential obstacles to locating relevant information on the Web

Obstacle	Notes
Too many search results	It can be difficult to accurately specify the concept to sufficient granularity and context within the search terms
Irrelevant search results	Problems may result from polysemy, context, and incidental use of search terms (particularly when the medical concept searched includes commonly used words)
Poor quality information (see Chapter 7.3)	The ease of Web publication readily allows anyone to do so, regardless of qualifications, knowledge, and ethics (but this is not unique to the Web)
Inability to identify the information source or their authority	There is no requirement for authors to provide this information
Inability to date the information	There is no requirement for authors to provide this information
Country-specific results bias	Results are often biased in favour of US resources, as this is where the most growth has been; this is also dependent upon the language of the search terms used
Poor retrieval of non-text media (pictures, sounds, movies, etc.)	Most automated indexing focuses on words within documents and throws away non-text data
Broken links in search results	When Web sites are updated, many links change; due to the vast size of the Web indices, it takes time for search engines to check and update included links

Web-based search engines

Search engines have two parts, the front-end 'query' interface presented to the user, and the back-end index or indices that the search terms are compared with.

Manual catalogues vs. automated indices

Web indexing, or the creation of these back-end indices, falls into two main categories: manual and automated. Manual indexing involves human operators that select and catalogue Web sites. Automated indexing uses computer programs (commonly called robots, 'bots', or spiders) to index the Web. One method cannot necessarily be considered superior to the other, as their relative merit is dependent on the type of information sought. Manual Web directories are generally better at locating whole Web sites relating to a particular topic, whereas computer-generated indices are generally better at locating individual Web pages.

Web portals

Manual indexing was the original method of indexing when fellow Web surfers shared the bookmarks (see Glossary) that they had collected by publishing them back to the Web. The most well known example of a bookmark-derived site is Yahoo!, started by two graduate students at Stanford University.

Manual indexing has the advantage that human indexers can still better judge the context and semantics of a particular site, and can provide annotations to the listings that assist in selecting a resource. This can be especially important in complex fields such as medicine, where the indexers can apply quality filters to the information that determine the merit of the site and whether or not it should be included in the index. This editorial role can be very valuable in screening out for the searcher a lot of the 'junk' that is picked up by automated search engines. However, the downside is that it is a very labour-intensive, time-consuming process and such indices cover but a fraction of the total Web.

General directories

The directory-based indices have evolved into the main access points to the Web. They are also referred to as portals, and this has become a ubiquitous model as everyone jockeys to become *the* homepage (p. 34) that everyone uses (although browsers are rarely customized, remaining set to the default installation page).

All directories have search engines that allow keyword querying of their directory. Due to the fact that manual indices only provide relatively small real coverage of the Web, many also partner with automated Web indices to provide additional results as well. Example general directories include:

Yahoo!:
http://www.yahoo.com/

Excite:
http://www.excite.com/

Netscape:
http://www.netscape.com/

Microsoft Network (MSN):
http://www.msn.com/

Medical directories

The major, general Web directories include medical and health subject areas with hierarchical subject structures that are easy to browse, and include simple search interfaces that allow keyword searching. These sites are focused on the general public although their depth of coverage can provide access to sophisticated health and medical resources. They can be a good resource if you are searching for various lists and collections (meta-directories—see below) in certain topic areas.

Health On the Net (HON) [2–4] is one of the older health- and medical-focused directories, having started in March 1996. MedHunt [5] is the search engine interface to the HON directory database, and HONSelect [6] is a new browsing interface that allows navigation of the MeSH tree (p. 184) and integrated searches of the HON database and MEDLINE (through PubMed, p. 186).

There are also a number of good medical indexes by US medical libraries and academic consortiums (e.g. MedWeb, HealthWeb) in addition to the commercially run ventures (e.g. Achoo, Health AtoZ). With regard to more UK-focused indexing efforts, OMNI (Organizing Medical Networked Information) is a health and biosciences portal within BIOME and is hosted at the Greenfield Medical Library, University of Nottingham.

Health on the Net:
http://www.hon.ch/

MedWeb:
http://www.medweb.emory.edu/

HealthWeb:
http://www.healthweb.org/

Achoo:
http://www.achoo.org/

Health AtoZ:
http://www.healthatoz.com/

OMNI:
http://omni.ac.uk/

There are also medical Web portals that are focused at healthcare professionals. The granddaddy of them all is Medical Matrix (see Fig. 1), begun collaboratively within the American Medical Informatics Association's Internet Working Group in 1994. The resource is now maintained by a

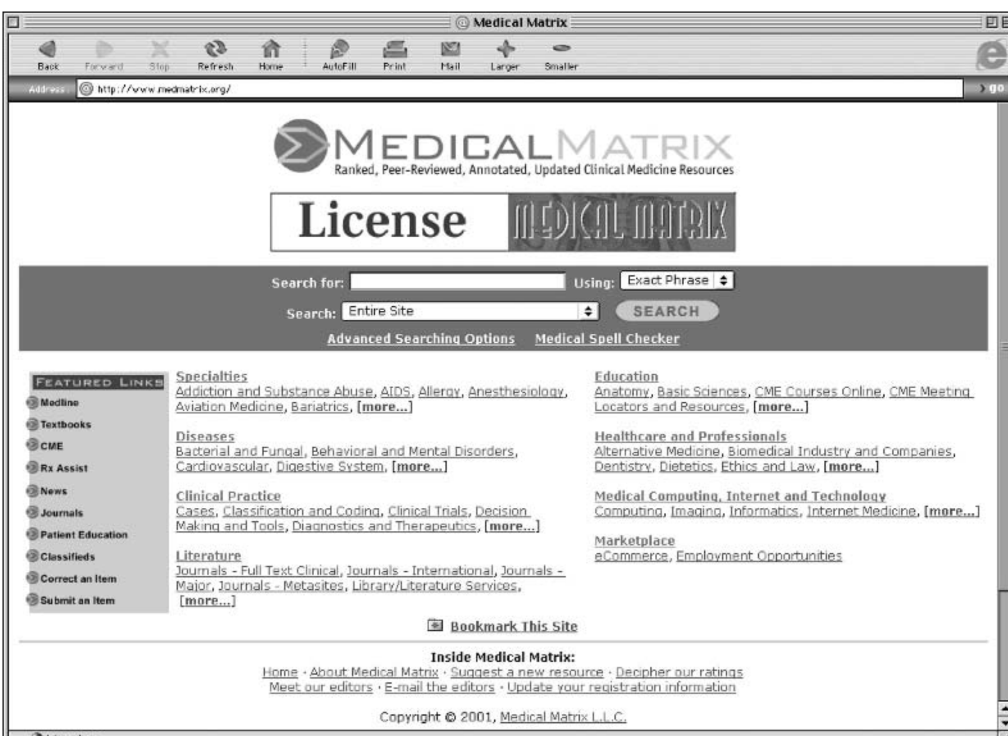

Fig. 1 Medical Matrix is one of the original projects cataloguing the Web for health professionals.

publisher, and directed through an editorial board and many section editors that review and rate selected sites according to a published rating scheme.

Another resource launched around the same time was Medscape, which provided not only links to other sources of medical information (i.e. a portal) but additionally editorialized and peer-reviewed content. It also provided a novel feature that allowed healthcare providers to provide their own commentary and feedback on the articles posted. There are now a number of other US-based healthcare professional sites including WebMD and MD Consult. Several UK-focused healthcare professional sites, such as Doctors.net.uk and ukpractice.net, complement these.

Medical Matrix:
http://www.medmatrix.org/

Medscape:
http://www.medscape.com/

WebMD:
http://www.webmd.com/

MD Consult:
http://www.mdconsult.com/

Doctors.net.uk:
http://www.doctors.net.uk/

ukpractice.net:
http://www.ukpractice.net/

Meta-directories

Meta-directories are 'directories of directories'. Many Web sites are in essence directories of links, and so it could be argued that sites such as Yahoo! are meta-directories. However, there are still some Web directory projects that take on more of the spirit of being a directory of other directories, rather than a directory of resources. The WWW Virtual Library (WWWVL) was one of the first, conceived in 1993 by the Web's founder, Tim Berners-Lee. Since cataloguing the Web was understood to be a monumental task, it made sense to distribute the task across many Web or 'virtual' librarians. Each librarian volunteers to maintain a catalogue in his or her area of expertise or interest.

The Open Directory Project is a similar venture using human editors to manage the directory of directories. The interesting aspect of this project is that the directory can be licensed and is used by a number of the major search engines. The Hardin Meta Directory is a medically focused meta-directory.

WWW Virtual Library:
http://vlib.org/

Open Directory Project:
http://dmoz.org/

Hardin Meta Directory:
http://www.lib.uiowa.edu/hardin/md/

Automated indices

Automated indices (e.g. AltaVista, Go.com, Excite, Looksmart, and Google) use computer programs or algorithms, commonly called robots or spiders, to index Web sites. Web robots traverse the Web by downloading a document and extracting all the words and URLs contained within. The words are all parsed and indexed against the document, and then all the URLs are identified and the process repeated for each link, excluding any that have already been indexed. The Internet search engines generally do not index any non-HTML pages, e.g. graphics or proprietary formats.

In this manner, robots attempt to index as much of the Web as possible. As the size of the Web is on the order of billions of pages and still growing at a geometric rate (approximately doubling every 6 months) [7,8], this is not a trivial task. The problem is not only one of covering this vast number of pages, but also of keeping the index up to date with the constant flux of information online.

Dynamically generated Web sites where the HTML is created from a database 'on the fly' and is not stored as an HTML file present another problem. The URLs for these pages are often temporary and only accessible with a login ID and password. Indexing robots rely on the fact that the URL will persist beyond the indexing process so that a search result will lead to relevant page. Any page that requires a login will automatically be off limits to an indexing robot.

When considering which search engine might best fit your needs it is useful to learn more about the indices that drive it (see Box 1). Is it created and maintained by human cataloguers or by arrays of high-speed computers? What are the criteria for inclusion and ranking in the index (e.g. listing fees, keywords, popularity, etc.)?

Box 1 Comparing search engines

Remember that running the same search using different search engines (or searchable directories) may result in different outcomes. That is, the various search engines can be complementary. A good resource on the status of Web search-engine technology is Search Engine Watch, particularly useful if you want to find out more about a particular search engine, who is behind it, and its relative strengths and weaknesses:

http://www.searchenginewatch.com/

Formerly a search engine would only query its own Web page index. However, competition has led to many partnerships and buy-outs of search engine companies. Some search engines like Lycos have even dropped their own index altogether in favour of a portal interface that relies on licensing content from other directories and indices.

AltaVista:
http://www.altavista.com/

Go.com:
http://www.go.com/

Excite:
http://www.excite.com/

Looksmart:
http://www.looksmart.com/

Google:
http://www.google.com/

Lycos:
http://www.lycos.com/

Medical automated indices

Obviously, with the huge number of Web pages available, it would make sense to have a search engine dedicated to a particular field of interest. Medically focused automated indices, like Marvin [2,5] and Medical World Search, fulfil this role. Marvin is part of HON MedHunt search engine and searches across the documents submitted to the HON directory [5]. Medical World Search focuses on medically relevant Web sites provided by medical directories such as Medical Matrix, and also uses a controlled medical language (i.e. MeSH) to index the works and phrases in a Web page.

Marvin/MedHunt:
http://www.hon.ch/

Medical World Search:
http://www.mwsearch.com/

Meta-search engines

With the large selection of search engines now available, an obvious need is to provide a single interface to simplify searching across a number of individual engines. At a basic level, this could take the form of a single Web page listing available search engines and providing a form for submitting the query to the engine of your choice. For example:

CUSI (Configurable Unified Search Engine):
http://cusi.emnet.co.uk/

A more complex interface can provide more integrated meta-searching allowing one query entry to access multiple search engines, compiling the results into one results page (e.g. DogPile, MetaCrawler, Search.com). These are server-based systems in that the search is submitted to the meta-search engine, which then manages the task of submitting it and compiling the results from the different search engines.

There are also client-based search systems (e.g. Sherlock) that allow users to search across multiple search engines from their computer desktop. The results are displayed in one window indicating which search engine, the title and the relevancy score (if available).

DogPile:
http://www.dogpile.com/

Metacrawler:
http://www.metacrawler.com/

Search.com:
http://www.search.com/

Sherlock:
http://www.apple.com/sherlock/

Challenges to information retrieval on the Web

As mentioned in the introduction to this chapter, the main disadvantage of information retrieval on the Web is that it is difficult to locate information effectively. This is due to several factors:

- **Lack of built-in indexing:** There is a lack of inherent indexing in the Web protocols. As a result the organization of medical information on the Web is very haphazard and ill-defined, and success in locating information can be as much the result of serendipity as of skill and experience.
- **The nature of human language:** One of the main problems with automated Web indexing engines is their inability to understand the nuances and complexities of language. Indexing the individual words in a document can lead to problems. Words can take on a different or similar meaning (polysemy, synonymy), can be dependent on the context used (the presence of surrounding words), or incidental to the main content (the presence of the word may not be relevant), and words combined together can take on independent meaning (phrases or concepts).
- **Quality:** There are many issues with respect to the quality of health and medical information online (see Chapter 7.3).

These are the underlying causes of the problems listed in Table 1 (p. 198).

Development of Web metadata

A potential solution to many of the above problems is a protocol for tagging documents with machine-readable identifiers that enable more precise searching. This 'data about data' is more commonly referred to as 'metadata'. This is nothing new to the field of library and information science where cataloguing has evolved to a fine art and metadata standards for the indexing of collections have been well developed.

Within the medical domain traditional databases, such as MEDLINE (Chapter 6.1), have from the outset used metadata tags to describe each item's characteristics (e.g. author, title, date of publication, etc.). The searching power of MEDLINE was further enhanced by the development of a controlled medical vocabulary, known as MeSH (Medical Subject Headings), to describe the content of the bibliographical item.

Web metadata standards have been proposed by a number of groups, including the Dublin Core (DC) Metadata Initiative [9,10] comprised of information scientists and librarians, among others. The DC metadata set consists of 15 elements (title, creator, subject description, publisher, contributor, date, type, format (MIME—p. 27), identifier (URL—p. 11), source, language, relation, coverage, and rights) and syntax for incorporating this metadata into a Web page.

Mapping Web pages to MeSH

Several Web directories have addressed the medical language problem by indexing sites using MeSH terms; e.g. CliniWeb [11,12], Karolinska Institutet's 'Diseases, disorders and related topics', CISMeF [13–15], and Health on the Net's HONSelect. The Web robot Medical World Search has also implemented MeSH indexing [16]. CliniWeb is illustrated in Fig. 2.

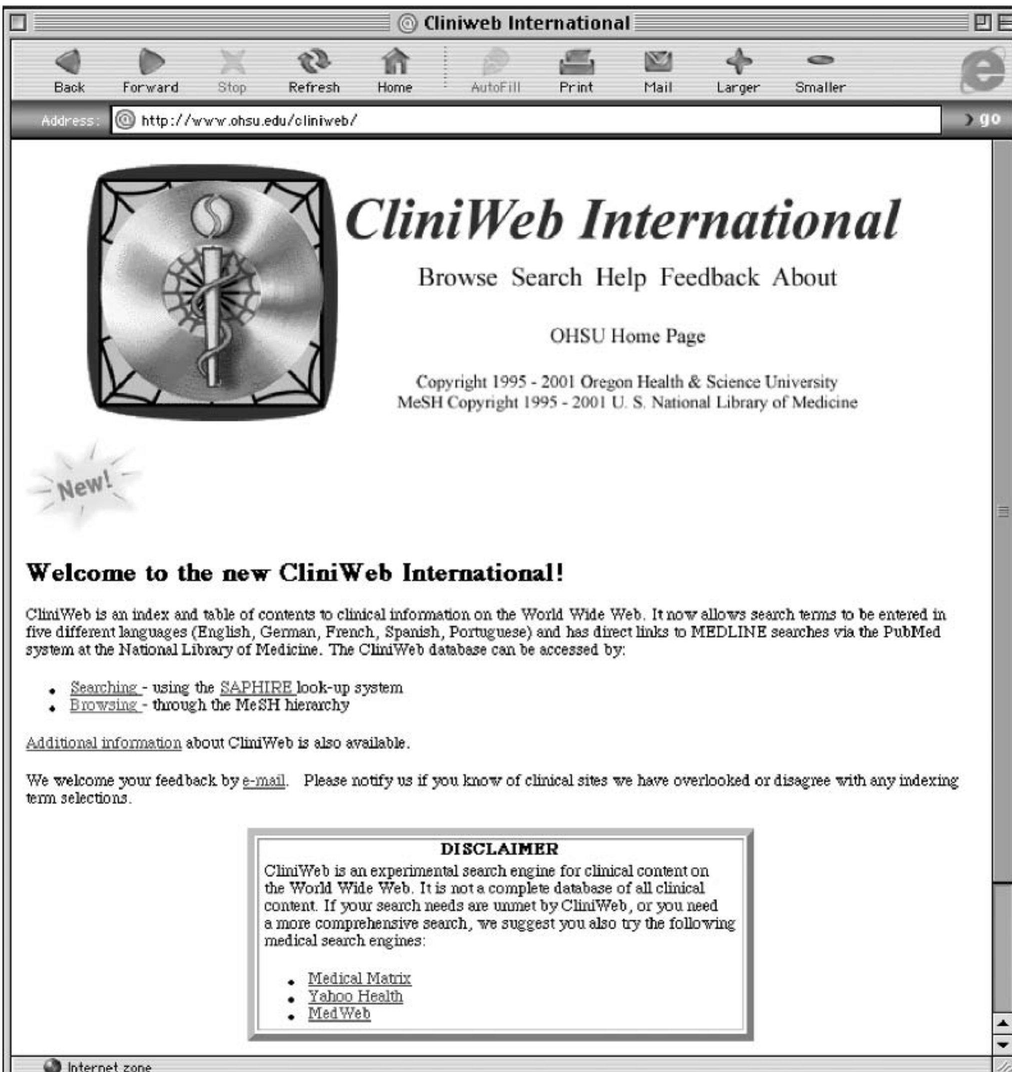

Fig. 2 CliniWeb is one of several efforts to map Internet content to the MeSH hierarchy (see text).

CliniWeb:
http://www.ohsu.edu/cliniweb/

Karolinska Institutet:
http://www.mic.ki.se/Diseases/

CISMeF:
http://www.cismef.org/

Medical Metadata

However, these efforts have been implemented independently and therefore lack consistency in their application. Medical Core Metadata (MCM) [17–20] is a proposed model that adopts the DC framework and extends it to the medical domain, currently providing schemes for two DC elements: DC.subject and DC.type. MCM-MeSHTerm (DC.subject) allows

Table 2 Locate relevant information by choosing an appropriate starting point

Requirement	**Resource type**	**Example resource**
Published medical literature (bibliography)	MEDLINE (see Chapter 6.1)	PubMed: http://www.ncbi.nlm.nih.gov/PubMed/
General health news from lay perspective	A consumer health portal	Achoo: http://www.achoo.com/
General medical news from a healthcare professional perspective	A healthcare professional portal	Medscape: http://www.medscape.com/ WebMD: http://www.webmd.com/
General speciality information	A medical (meta-) directory site	Medical Matrix: http://www.medmatrix.org/ CliniWeb: http://www.ohsu.edu/cliniweb/ Karolinska's 'Diseases and Disorders': http://www.mic.ki.se/Diseases/index.html
Very specific keywords	A search engine	Marvin/MedHunt: http://www.hon.ch/ Medical World Search: http://www.mwsearch.com/ Google: http://www.google.com/

for the tagging of Web resources with MeSH terms, and MCM-Resource-Type (DC.type) with medical resource types, such as image archives, grant proposals, case reports, etc. One of the challenges in the implementation of metadata is in how it is assigned to Web resources. One option is for authors to assign terms, since they are most familiar with the content—but they are also more likely to inconsistently or incorrectly assign metatags. The alternative is to have professional cataloguers apply the metatags. However, the problems of manual indexing of the Web have already been discussed and are still applicable here. MCM is still under development and needs wider discussion and collaboration to create a more robust and stable schema likely to gain broad adoption, and to determine how best to implement it.

The future

The foretelling of intelligent software 'agents' that will automatically hunt down information for us online has been around for sometime, but it remains to be seen when such technology will become widely available. The meta-search engines are currently the closest alternative we have, and Apple's Sherlock search engine brings this technology to the desktop with the ability to store searches and re-run them on a regular basis. We can expect this type of facility to become increasingly integrated into computer operating systems and/or browser software. In the meantime, choosing an appropriate place to start looking (see Table 2) remains essential when searching for medical information on the Web.

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6.3 Facilitating research

Gunther Eysenbach and Jeremy Wyatt

This chapter concerns the use of the Internet in the research process, from identifying research issues, through using the Web for surveys and clinical trials, to pre-publishing and publishing research results. Although literature searches using databases such as MEDLINE are obviously an important and integral part of every research process, this is considered in Chapter 6.1.

Identifying issues for qualitative research

As the most comprehensive archive of written material representing our world and people's opinions, concerns, and desires (in industrialized countries), the Internet can be used to identify 'issues' for qualitative (descriptive) research and to generate hypotheses. Material published on the Internet may be a valuable resource for researchers desiring to understand people and the social and cultural contexts within which they live—outside of experimental settings—with due emphasis on the interpretations, experiences, and views of 'real world' people. Reviews of information posted by consumers on the Internet may help to identify health beliefs, common topics, motives, information, and emotional needs of patients, and point to areas where research is needed. Comparing recommendations found on the Web against evidence-based guidelines is one way to identify areas where there is a gap between opinion and evidence, or where there is a need for clinical innovation.

The accessibility of information for analysis and the anonymity of the Internet allow researchers to analyse text and narratives on Web sites, to use newsgroups as global focus groups, and to conduct interviews and surveys via e-mail, chat rooms, Web sites, or newsgroups. Topics suited to qualitative research include:

- Analysis of interactive communications (e.g. e-mail).
- Study of online communities (virtual self-help groups, newsgroups, mailing lists).

- Investigation of communication processes between patients and professionals.
- Study of consumer preferences, patient concerns, and information needs.
- Exploration of the 'epidemiology of health information' on the Web [1,2].

The Internet population is unrepresentative of the general population, restricting the use of the Internet for quantitative studies (i.e. studies focusing on measurement). Qualitative studies, however, do not require representative samples: 'In qualitative research we are not interested in an average view of a patient population, but want to gain an in-depth understanding of the experience of particular individuals or groups; we should therefore deliberately seek out individuals or groups who fit the bill' [3]. Three different research methodologies for qualitative research on the Internet may be distinguished:

- **Passive analysis:** For example, studying information on Web sites or interactions in newsgroups, mailing lists, and chat rooms—without researchers actively involving themselves.
- **Active analysis:** Also called participant observation; the researcher participates in the communication process, often without disclosing their identity as researcher. For example, they may ask questions in a patient discussion group implying that she or he is a fellow patient. Such studies often involve elements of deception, unless the researcher is a sufferer him- or herself.
- **Interviews and surveys:** See below.

Examples of these three types of qualitative research on the Internet are available elsewhere [1].

Using the Internet for surveys

Using the Internet for surveys requires an awareness of methodologies, selection bias, and technical issues.

Methodological issues

Internet-based surveys may be conducted by means of interactive interviews or by questionnaires designed for self-completion. Electronic one-to-one interviews can be conducted via e-mail or using chat rooms. Questionnaires can be administered by e-mail (e.g. using mailing lists), by posting to newsgroups, and on the Web using fill-in forms.

When e-mail is used to administer questionnaires, messages are usually sent to a selected group with a known number of participants, thus allowing calculation of the response rate. Surveys posted to newsgroups may request that the completed questionnaire is posted back to the researcher, but it is impossible to know who and how many people read the questionnaire. If Web-based forms are used, questionnaires can be placed in a password-protected area of a Web site (i.e. participation by invitation or registration only), or alternatively they may be open to the public (i.e. any site visitor can complete the survey). The latter option makes calculation of a response rate more difficult but not impossible: the number of people who access (without necessarily completing) the questionnaire is counted and used as the denominator. Web-based surveys have the advantage that the respondent can remain anonymous (as opposed to e-mail surveys, where the e-mail address of the responder is revealed). Furthermore, they are very convenient for the researcher, as responses can be directly stored in a database where they are immediately accessible for analysis.

Electronic interviews and surveys ('e-surveys') are emerging scientific research methodologies, pioneered by communication scientists, sociologists, and psychologists, although their use for health-related research is still in its infancy [4–10]. Examples of health-related research include:

- A Web-based survey on the effects of ulcerative colitis on quality of life [11].
- Collection of clinical data from atopy patients [12].
- A Web-based survey looking at complementary and alternative medicine use by patients with inflammatory bowel disease and Internet access [13].
- A survey of dentists regarding the usefulness of the Internet in supporting patient care [14,15].

E-surveys may be part of a qualitative research process, but results can be analysed quantitatively as long as researchers are aware of potential bias (see below). In addition to gathering data, the Internet may also be used in the course of developing questionnaires, as it allows rapid prototyping and pilot testing of instruments, e.g. to evaluate the effect of framing the questions differently [16].

Several studies have checked the validity of Web-based surveys by comparing the results of studies conducted on the Web with identical studies in the real world. These seem to suggest that the validity and reliability of data obtained online are comparable to those obtained by classical methods [4,5,17–19]. However, issues of generalizability (mainly due to selection bias, discussed in detail below) remain important considerations, and the researcher should select his or her research question and interpret the results with care. The benefits and problems of Web-based surveys have been summarized by Wyatt, who suggests guidelines for when they may be appropriate (see Box 1) [20].

Box 1 Guidelines for Web-based surveys

Scenarios that may be suitable for a Web-based survey

Respondent features:

- Respondents are already avid Internet users; e-mail addresses known for reminder messages.
- Respondents are enthusiastic form fillers; will not require monetary incentives.
- Need for respondents covering a wide geographical area (e.g. rare clinical specialties, diseases).
- Respondents are known to match non-respondents and even non-Internet users on key variables.

Survey features:

- Need for complex branching, interactive questionnaire or multimedia as part of the survey instrument.
- Survey content will evolve fast (e.g. Delphi method surveys use repeating rounds of revised questionnaires delivered over a short period, incorporating aggregate results from previous rounds until convergence is achieved).
- Intent is to document bizarre, rare phenomena whose simple occurrence is of interest.
- No need for representative results: collecting ideas vs. hypothesis testing.

Investigator features:

- Limited budget for mailing and data processing, but good in-house Web skills.
- Precautions can be taken against multiple responses by same individual, password sharing.
- Web survey forms have been piloted with representative participants and demonstrate acceptable validity and reliability with most platform, browser, and Internet access provider combinations.
- Data is required fast in a readily analysed form.

Scenarios that are unsuitable for a Web-based survey

Respondent features:

- Target group is under-represented on Internet; e.g. the underprivileged, elderly people.

continued

Box 1 continued

- Target group is concerned, however unreasonably, about privacy aspects.
- Target group requires substantial incentives to complete the survey.
- Need for a representative sample.

Survey features:

- Need for very accurate timing data on participants (inaccuracies in the range of seconds are added due to network transmission times, unless JavaScript or Java applets are used; see Glossary) or observational data on participants.
- An existing paper instrument has been carefully validated on target group.
- Need to capture qualitative data or observations about participants.
- Wish to reach the same group of participants in the same way months or years later.

Investigator features:

- Limited in-house Web or Java expertise but existing desktop publishing and mailing facility.

Selection bias

In 'open' surveys conducted via the Internet where Web users, newsgroup readers, or mailing list subscribers are invited to participate by completing a questionnaire, selection bias is a major factor limiting the generalizability (external validity) of results. Selection bias occurs due to:

- The non-representative nature of the Internet population.
- The self-selection of participants, i.e. the non-representative nature of respondents, also called the 'volunteer effect' [21].

The non-representative nature of Internet demographics was briefly considered in Chapter 1.4. Considering whether the topic chosen for study is suitable for the Internet population is the first and probably the most important step in minimizing bias, thus maximizing response rates and increasing the external validity of the results [20]. For example, targeting elderly homeless alcoholics is unsuitable for an Internet survey and the results are likely to be heavily skewed by hoax responses.

Self-selection bias originates from the fact that people are more likely to respond to questionnaires if they see items which interest them, e.g. because they are affected by the items asked about, or because they are attracted by the incentives offered for participating. As people who respond almost certainly have different characteristics than those who do not, the results are likely to be biased. This kind of selection bias is more serious than the bias arising from the non-representative nature of the population, because the researcher deals with a myriad of unknown factors and has little opportunity to interpret his or her results accordingly. Such bias may be exacerbated via loaded incentives (e.g. typical 'male' incentives such as computer equipment). Evidence suggests women are generally more interested in health topics and exhibit more active information-seeking behaviour [22], so are more likely to volunteer participation in health questionnaires. For Web surveys, the potential for self-selection bias can be estimated by measuring the response rate, expressed as the number of people completing the questionnaire divided by those who viewed it (cf. the participation rate, expressed as the number of site visitors viewing the questionnaire divided by the total number of site visitors).

Technical issues

Although a detailed analysis is beyond the scope of this chapter, a synopsis of important techniques and tips for implementing Web-based surveys provides some insight into the difficulties faced by survey designers (see Box 2).

Box 2 Technical issues in implementing Web-based surveys

Use of 'cookies'

Cookies can assign a unique identifier to every questionnaire viewer, useful for determining response and participation rates (see text), and for filtering out multiple responses by the same person. As cookies may be regarded with suspicion, we recommend that researchers openly state that cookies will be sent (and the reasons for this); set the cookie to expire on the day that data collection ceases; and publish a privacy policy (p. 127).

Measuring response time

The time needed to complete a questionnaire can be readily calculated by subtracting the time a form was called up by the browser from the time it was submitted using an automatic time-stamp. The response time may be used to exclude respondents who fill in the questionnaire too quickly: this may identify hoax responses, where respondents don't read the questions.

Avoiding missing data

Forms can be configured to automatically reject incomplete questionnaires and point out missing or contradictory items. Checks can be made on the client (p. 9) prior to submission, or following submission to the server (where incomplete responses can also be analysed, e.g. during a questionnaire pilot).

continued

Box 2 continued

Maximizing response rate

The number of contacts, personalized contacts, and contact with participants before the actual survey are the factors most associated with higher response rates in Web surveys [23]. Incentives increase the risk of selection bias (see text), but less so if cash is offered. Perhaps the best incentive (and the easiest to deliver via the Internet) is the promise of survey results or personalized answers (e.g. a score). The option to complete questionnaires anonymously avoids wariness associated with requests for personal information (e.g. an e-mail address), but increases the risk of hoax responses. Researchers should be open about who is behind the study, what the aim is, and provide opportunities for feedback. Although postal surveys are superior to e-mail surveys with regard to response rate, online surveys are much cheaper [24,25]. Schleyer [15] estimated that the cost of their Web-based survey was 38 percent less than that of an equivalent mail survey and presented a general formula for calculating break-even points between electronic and hard-copy surveys. Jones gave figures of 92 p per reply for postal surveys, 35 p for e-mail, and 41 p for the Web [24].

Randomizing items

Scripting languages may be used to build dynamic questionnaires (as opposed to static forms) that look different for certain user groups or which randomize certain aspects of the questionnaire (e.g. the order of the items). This can be useful to exclude possible systematic influences of the order of the items upon responses.

Ethical issues

The ethical issues involved in any type of online research should not be forgotten [1,26–31]. These include informed consent as a basic ethical tenet of scientific research on human populations [32], protection of privacy, and avoiding psychological harm.

In qualitative research on the Web, informed consent is required when:

- Data are collected from research participants through any form of communication, interaction, or intervention.
- Behaviour of research participants occurs in a private context where an individual can reasonably expect that no observation or reporting is taking place, except when researchers do research 'in public places or use publicly available information about individuals (e.g. naturalistic observations in public places, analysis of public records, or archival research)' [33].

The question therefore arises of whether researchers analysing newsgroup postings enter a 'public place', or whether the space they invade is perceived as private. In the context of research, the expectation of the individual (whether he/she can reasonably expect that no observation is taking place) is crucial. Different Internet services have different levels of perceived privacy (in decreasing order of privacy: private e-mail; chat rooms; mailing lists; newsgroups; Web sites). The perceived level of privacy is a function of the number of participants, but also depends on other factors such as group norms established by the community to be studied. For example, in a controversial paper, Finn studied a virtual self-support group where the moderator was actively discouraging interested professionals who were not sexual abuse survivors from joining the group [34]. In those cases, obtaining informed consent (or seeking an ethical waiver, if the research could not practicably be carried out were informed consent to be required) is mandatory.

In practice, obtaining informed consent, especially for passive research methods, is difficult, as researchers usually cannot post an announcement to a mailing list or newsgroup saying that it will be monitored and analysed for the next few months, as this may greatly influence or even spoil the results, and because the mere posting of such a request may disrupt the community, and therefore be considered unethical. Researchers should therefore first obtain consent from a group moderator in order to explore whether even a request for permission is felt to be disruptive to the group process. If the moderator or person responsible for the list has no objections, one may then post a message to a newsgroup or mailing list explaining the purpose of the research, explaining that one will observe the community, assuring all participants of anonymity, and giving them the opportunity to withdraw from the newsgroup or mailing list or to exclude themselves from the study by writing to the researcher. The fundamental problem is that this may influence the communication process and may even destroy the community. Besides, participants who later join the group need to get the same information. An alternative would be to analyse the communication retrospectively and to write individual e-mails to all participants whose comments were to be analysed or quoted, asking for permission to use them; this technique has been used by Sharf [35].

In any case, researchers should make themselves familiar with the virtual community they are approaching; i.e. read the messages in a newsgroup for some time ('lurking'). Under no circumstances should researchers blindly spam (p. 31) or cross-post requests for research participation to various newsgroups.

Informed consent may also play a role when researchers report aggregate (collated and hence anonymous) data on usage patterns, such as a log-file analysis (reporting data on what Web sites have been accessed by a population). Crucial here is an appropriate privacy statement stating that these data may be analysed and reported in aggregate [28]. Note that aggregate data are exempt from the registration requirements of the UK's Data Protection Act of 1998 (see Chapter 3.4).

In conducting surveys researchers may obtain informed consent by declaring the purpose of the study; disclosing which institutions are behind the study; explaining how privacy will be assured; and detailing with whom data will be shared and how it will be reported, before participants complete the questionnaire.

When reporting results, it is obvious that the total anonymity of research participants needs to be maintained. Researchers have to keep in mind that, by the very process of quoting the exact words of a newsgroup or mailing list participant, the confidentiality of the participant may already be broken as Internet search engines (see Chapter 6.2) may be able to retrieve the original message, including the e-mail address of the sender. It is essential, therefore, to ask participants whether they agree to be quoted whenever there may be a retrievable archive, pointing out the risk that they may be identifiable. Problems can also potentially arise from just citing the name of the community (e.g. of a newsgroup), which may damage the community being studied.

Finding methods, protocols, and instruments

For laboratory 'bench work', researchers often need a protocol for a specific assay method. In addition to the possibility of searching literature databases, there are also specialized services on the Web that can assist in this research, such as MethodsFinder and the 'Technical tips online' database at BioMedNet:

MethodsFinder (BIOSIS):
http://www.methodsfinder.org/

BioMedNet:
http://www.bmn.com/

Sometimes asking a specific question on the right newsgroup or mailing list is also very effective. Clinical researchers may be more interested in instruments to measure patient outcomes. An excellent guide to selecting quality-of-life instruments is the Quality of Life Instruments Database at the Mapi Research Institute:

http://www.qolid.org/

Online statistical analysis tools are available at the Simple Interactive Statistical Analysis (SISA) Web site, while background information is available within the online book *Statistics at square one*:

SISA (Daan Uitenbroek):
http://home.clara.net/sisa/

Statistics at square one (*British Medical Journal* Publishing Group):
http://www.bmj.com/collections/statsbk/

Protocols of clinical trials, which may be useful for researchers developing their own protocols, can be found in some of the clinical trial databases available on the Web, as described below.

Clinical trials and the Web

The Web is being used to assist in the identification and conduction of clinical trials.

Identifying trials

To prevent unintended duplication of clinical research, detect underreporting of research, and ease the work of systemic reviewing, it has been suggested that we should prospectively register clinical trials [36–39]. It is, however, unlikely that there will ever be one complete centralized multinational database. Instead, multiple resources set up by numerous different organizations will exist [40]. Internet technology will play a central role in linking these databases and making this information available to researchers and patients. Some scenarios in which a search of trial databases may be useful:

- A researcher wants to conduct a randomized controlled trial and wants to know whether anyone else is already running one on the same topic.
- A physician has a patient who is asking about available trials.
- A patient is looking for ongoing trials.
- A researcher is looking for possible participants for his trial.
- A researcher doing a systematic review is looking for unpublished trials.

Information about ongoing and completed clinical trials is increasingly being published on the Internet, and searches on the Web may be a useful means of complementing traditional bibliographic searches if authors of systematic reviews wish to find ongoing or unpublished trials [41].

Researchers use their personal or department home pages to announce their interest in a certain research area or to recruit patients [42]. Journals like *The Lancet* have begun to publish research protocols on their Web site [43], and more and more researchers will also publish 'pre-prints' (p. 239) of their findings on the Web [44].

Consumers and patient organizations also have an interest in disseminating information about ongoing trials; e.g. the National Alliance of Breast Cancer Organizations:

http://www.nabco.org/

Government and funding agencies react to this need by establishing trial databases for consumers; e.g. the US National Institutes of Health searchable database [45]:

http://ClinicalTrials.gov/

Commercial enterprises also help researchers to recruit patients, or help patients to find clinical trials. For example:

CenterWatch Clinical Trials Listing Service (CenterWatch, Inc.):
http://www.centerwatch.com/

ClinicalTrialFinder.com (Clinical Data Technologies Ltd):
http://www.clinicaltrialfinder.com/

Current Controlled Trials (BioMed Central):
http://www.controlled-trials.com

Pharmaceutical companies and industry associations have likewise begun to recognize that openness and access to information on clinical trials and new drug developments can improve patient care and are part of social responsibility [46]. For example:

Clinical Trials Register (GlaxoSmithKline):
http://ctr.glaxowellcome.co.uk/

Search for Cures (Pharmaceutical Research and Manufacturers of America):
http://www.phrma.org/searchcures/

Finally, information or databases on ongoing clinical trials can often also be found on disease-specific sites. For example:

Canadian HIV Trials Network:
http://www.hivnet.ubc.ca/ctn.html

CancerNet (National Cancer Institute):
http://cancernet.nci.nih.gov/

Conducting trials on the Web

The Web is increasingly being used in the course of conducting large-scale multi-centre clinical trials (e.g. for remote randomization and data entry), and in the distribution of information on trial progress or protocols [47–48]. Trial centres may enter patient data using Java applets (see Glossary) that encrypt data and send it to the data centre via the Internet [49–52], where the data are stored and randomized, returning for example a study number and randomization information.

Pre-publishing and publishing research

As discussed in Chapter 7.1, traditional publication is a well-defined event, whereas 'publication' in the electronic age is much more of a continuum [53], reflecting and occurring during the entire research process from hypothesis formulation to data gathering, interpretation, and the presentation and discussion of the final results. In order to distinguish online collaborative 'work in progress' from 'final' peer-reviewed publication we may term the former 'Type 1' and the latter 'Type 2' electronic publication [54]. Here, peer review is not the distinguishing characteristic: in Type 1 publication a 'post-publication' peer review process takes place. Type 2 publication will ordinarily take place in online journals (see Chapter 7.1). The following scenarios illustrate how researchers might use Type 1 electronic publication on the Internet:

- Sending and discussing preliminary results on mailing lists.
- Publishing drafts of scientific papers on pre-print/e-print sites (p. 239) in order to solicit comments and to improve the manuscript.
- Publishing data and information in databases; e.g. nucleotide sequences in the EMBL/Genbank databases.
- Publishing clinical trial protocols and raw data in a 'trial bank' [55].

Current awareness services

Electronic editions of paper journals and 'stand alone' e-journals typically offer subscriptions to 'TOC alerts', where users receive a table of contents by e-mail as soon as a new issue appears. The more sophisticated systems allow users to specify their interests using a controlled vocabulary, enabling the system to screen each newly published article for certain keywords or citations. Examples of current awareness services include:

Customised @lerts (*British Medical Journal*):
http://bmj.com/cgi/customalert/

JournAlert (Doctors.net.uk):
http://www.doctors.net.uk/

Journal Watch (Massachusetts Medical Society):
http://www.jwatch.org/

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7 Using the Internet for publishing and commerce

iNFOpulse

Medical publishing

- The Internet offers rapid publication; 'live' cross-reference links; and greater interaction between journals and their readers.
- Most journals presently replicate some or all of their content onto Web pages and add a search engine; others are using the Internet to improve traditional publishing practices, devising new ways of delivering content with additional features.
- The peer-review process is revolutionized by unlimited publication space; greater interactivity between editors, authors, and reviewers making peer review an ongoing process of comment and revision (rather than a one-off event); and the possibility of an openness that offers greater accountability and higher standards of ethical behaviour.
- E-prints (Web versions of papers not yet peer-reviewed) enable an author to revise his or her article before submitting it to a journal for formal peer review.
- Free or low-cost access to online journal content can be achieved, as although journals receive research and peer review for free, they formerly needed to charge subscriptions to cover costly printing and distribution.

Medical commerce

- 'E-health' is used to denote the application of e-commerce to healthcare and has both advantages (particularly for procurement of goods and services) and disadvantages as a business model.
- As an example of e-health activity, pharmaceutical companies utilize the Internet throughout product cycles, using it as a vehicle for professional sponsorship, 'e-detailing', and direct-to-consumer (DTC) marketing. Online DTC retailing and 'e-prescribing' are natural follow-on activities.
- Pharmaceutical company Internet activities highlight many of the regulatory issues that apply to e-health in general. Protecting consumers is challenging due in part to the unique characteristics of the Internet as a medium.
- Ethical e-health practices respect the principles of candour; honesty; quality; informed consent; privacy; professionalism in online healthcare; responsible partnering; and accountability.

continued

Information quality issues

- An all-purpose definition for 'quality' healthcare information on the Internet is difficult, but probably denotes content that is accurate; well designed; makes relevant disclosures; date-stamped; authoritative; easy to use; accessible; and available.
- A number of studies have demonstrated that misleading or incomplete healthcare information is rife on the Internet, partly attributable to the unique characteristics of the medium.
- Several initiatives are focusing on endowing consumers with the necessary skills to filter and appraise information for themselves.
- Advertising adherence to voluntary codes of practice is the principal means of self-labelling employed by content providers.
- Endorsement of an information provider by a third party may take the form of a kitemark, or linkage from a portal site. Both methods of third-party labelling have potential advantages and disadvantages, including uncertainty over the validity of third-party evaluations.
- Sites publishing misinformation, ignoring stated codes of practice, or misusing kitemarks present a complex enforcement problem.

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7.1 Medical publishing

Fiona Godlee and Pritpal S. Tamber

A few years ago, online journals were simply Web-based versions of printed journals, together with a search engine. Basic though they were, they did have some advantages:

- being able to search through old issues of the journal;
- being able to 'click' from article to article, some of which may have been published years apart;
- no longer needing to have shelves filled with journals;
- being able to 'bookmark' important articles enabling you to return to them at any time;
- no longer having to wait for the postal service to deliver the journal on time.

But the Internet has more to offer than simply replicating content to sit inside a computer [1]. In general, it provides:

- speed;
- the ability to link from anywhere to anywhere;
- greater opportunity for interaction between journals and their readers.

In the past few years medical journals have begun to explore how they can use the functionality that the Web offers to save clinicians time. At varying speeds, they have begun to transform from static pages of text to dynamic, interactive places. In this chapter we will describe how journals have evolved, and also how the Internet has offered a completely new and potentially revolutionary approach to medical publishing.

Recent journal evolution

The best way to describe the evolution is through an example. Letters are an important part of journals because they reflect the opinions of the medical community at large, rather than a minority of authors and editors.

The traditional way they are handled is:

Step 1 Journal is printed.
Step 2 Journal is posted out to subscribers.
Step 3 People read the papers, write letters, and post them.
Step 4 Journal receives the letters, waits to see how many arrive and what points are made.
Step 5 Journal decides which letters should be published in the limited space they have.
Step 6 A sample of letters are published.

This entire process can take months. Step 4 is the most time consuming, but also the most important. By waiting, journals ensure they have collected the opinions of as many people as possible. The letters can then be published in one issue of the journal rather than spread out over a few issues, making it easier for them to be found at a later date.

Publishing on the Web means the journal can be received worldwide instantaneously—steps 1 and 2 are therefore eliminated. Then, rather than writing letters on paper, people can write e-mails. It takes seconds to deliver an e-mail as opposed to the days it may take to deliver a letter, especially from abroad. But saving time is only the beginning of what the Internet has to offer.

The Web enables letters to be linked to the article they are commenting on, so there is no need for step 4. What's more, given that Web space is unlimited, all letters can be published so there is no need for step 5 (other than screening out offensive or libellous comments). This way, everybody gets their say, the letters can be found easily, and it's all done quickly.

Journal communities

As well as offering greater functionality *within* journals, the Web offers possibilities for interactivity *between* journals [1–7]. At the time of writing, there are four communities of journals on the Web: HighWire Press, Science Direct, the Open Archives Initiative, and PubMed Central. There are also other initiatives based upon the opportunities created by the Internet, such as CrossRef and SPARC.

What is HighWire Press?

Run by Stanford University Libraries, it develops and maintains the Web versions of journals in medical, physical, social, and life sciences:

http://highwire.stanford.edu/

The Press began in 1995 by producing the online version of the *Journal of Biological Chemistry*, at the time the most highly cited and second largest peer-reviewed journal in the world. The success of the online version of this journal soon inspired others to join HighWire Press, including *Science*, the *Proceedings of the National Academy of Sciences of the United States of America*, and the *British Medical Journal* (see Fig. 1).

Stanford University began HighWire Press in response to concerns that scientific societies (as publishers of journals) would lack the resources and expertise required to move their publications onto the Web. With everyone offering online versions, and the Internet being considered the future, this would have rendered journals invisible—a dangerous predicament in an industry where being read and cited is the key to success. Stanford University also felt that assistance for journals should come from the academic rather than the commercial publishing community. For years, commercial publishers have been accused of raising prices, taking advantage of the fact

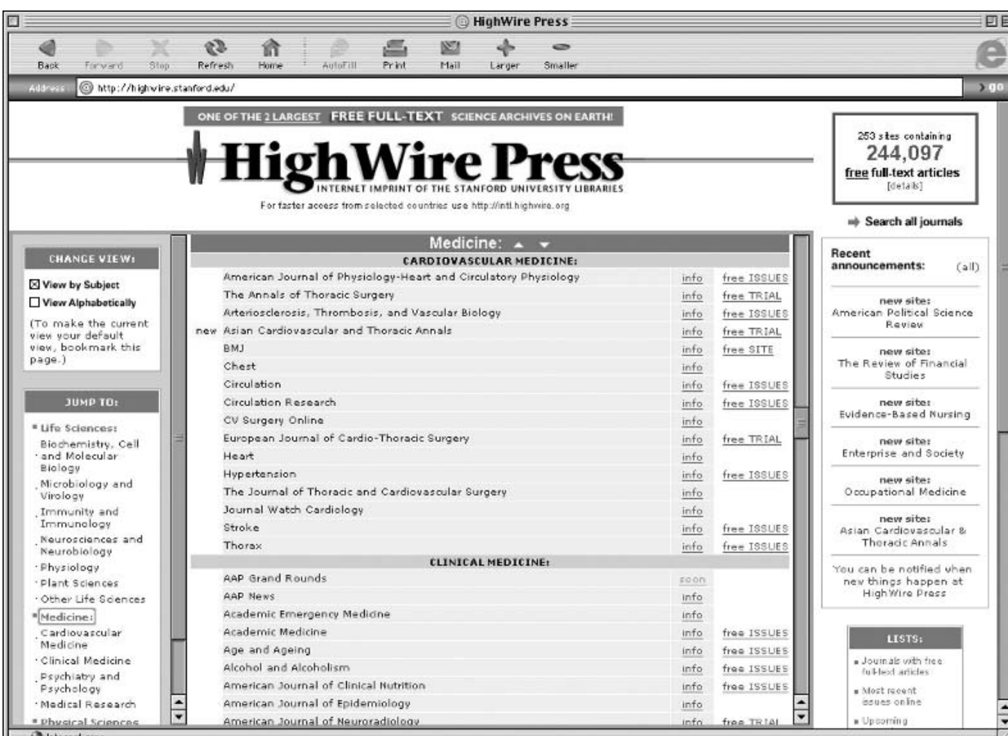

Fig. 1 The HighWire Press Web site provides unrestricted full-text access to many articles over a year old and some current articles from a minority of journals.

that researchers have no choice but to subscribe to their journals [8]. Stanford University describes HighWire Press as a 'partner, agent of change, and advisor' to the science community [9].

But HighWire does not just give journals the chance to have an online version; it also looks to provide added dimensions to the information in a printed journal by offering:

- links between authors, articles, and citations;
- advanced searching capabilities;
- high-resolution images, multimedia, and interactivity.

Linking citations in turn enables the reader to:

- read related articles in the same journal;
- find abstracts of related articles in PubMed (see Chapter 6.1);
- be alerted when new articles cite the one he or she is reading.

Say, for instance, you read a contentious article on the management of hypertension. Reading related articles in the same journal will tell you if this is a new way of thinking or part of an ongoing debate. However, you may want to see what is being said in other journals, so you need to find abstracts of related articles in PubMed—a bibliographic database that includes MEDLINE (see Chapter 6.1). Once you've digested all that has been written to date, it would be nice to stay abreast of further developments. By giving your e-mail address to the journal, it will automatically e-mail you when new articles cite the ones you were reading. Such 'alerting' services are considered further in Chapter 6.3.

HighWire Press, however, has no say in the subscription policies of the journals it hosts. Some journals allow users to read their content for free, some ask for a subscription but will allow free access to old material, and some ask for a subscription to all of their content. If you search HighWire's clinical medical journals for 'hypertension', one of the citations is from the *British Journal of Ophthalmology* (*eBJO*). Clicking on the link for the 'full text' of this article takes you to the *eBJO*'s sign-in page where you can only proceed if you, or your institution, have a subscription. If you do not, you can only view the abstract. This is quite frustrating, and analogous to a helpful librarian taking you through a maze of corridors to a journal containing the citation you are after, and then saying you cannot read it—at least not without paying. So, although HighWire Press says you can search across 227 journal sites (at the time of writing), you are still restricted in terms of what you can actually see as not many journals offer their content for free.

Of course, for journals to survive they have to charge. And, to be fair, HighWire Press does its best to give users access to as many articles as possible. It encourages journals to make their 'old' material free to access. At present many journals on HighWire make their content free to access a year after publication, striking a compromise between maintaining subscription revenue and making information easier to find online.

What is ScienceDirect?

ScienceDirect is owned by the publisher Elsevier Science. Elsevier is the world's largest publisher of science and technology information and has over 1100 journals, including *The Lancet*. ScienceDirect was launched in 1997 as a way for institutions to subscribe to as many Elsevier journals as they wished. The service offers online access to about a million full text articles, dating back to January 1996:

http://www.sciencedirect.com/

What is the Open Archives Initiative?

An alternative approach to freeing up the scientific literature is self-archiving, long advocated by Steve Hanard, Professor of Cognitive Science at the University of Southampton [10]. Hanard encourages scientists to continue publishing with traditional publishers but also to publish their work on their own Web sites. The difficulty users face in finding such self-archived material is now being tackled by the Open Archives Initiative (OAI), founded by a group of librarians and computer scientists:

http://www.openarchives.org/

The OAI is developing systems that link individual archives, creating a globally distributed archive that users can search across all disciplines.

What is PubMed Central?

PubMed Central is the open access repository of full text peer-reviewed research established by the US National Institutes of Health:

http://www.pubmedcentral.nih.gov/

PubMed Central aspires to become a full-text extension to the abstract-only PubMed service (see Chapter 6.1), allowing users barrier-free access to the full text of all the peer-reviewed content of included journals. The success of PubMed Central depends on the willingness of publishers to contribute their peer-reviewed content free of charge, which raises obvious concerns about protecting revenues from subscriptions [11]. Why, the argument goes, should anyone pay for the journal when they can access its contents free through PubMed Central?

The journals that have joined PubMed Central have clearly decided that it is in their best interests—as well as the best interests of science—to do so [12]. The first big journal to give their research papers to PubMed Central was the *Proceedings of the National Academy of Sciences of the United States of America*, soon followed by the *British Medical Journal*.

What is CrossRef?

CrossRef is not actually a collection of journals but a service that enables links between articles:

http://www.crossref.org/

It does this by assigning each article a number called a 'digital object identifier' (DOI). It was developed by two publishers, Wiley and Academic Press, and launched in February 2000. The group of publishers now involved in CrossRef call themselves the 'Publishers International Linking Association' (PILA). They pay an annual fee to be part of the Association, for which they have DOI numbers assigned to their articles.

Although CrossRef contains a large number of journals and articles (more than any other initiative) it is mainly of interest to publishers looking for ways to link their articles. For users, however, whether you go from the full text of one article to the full text of another will depend on whether you have subscribed to the journal you are going to. If not, you are faced with the sign-in page of the journal.

What is SPARC?

SPARC stands for the Scholarly Publishing and Academic Resources Coalition, and was founded by the Association of Research Libraries (ARL) in the USA:

http://www.arl.org/sparc/

Again, this is not a collection of journals. It is a pressure group that aims to fight high journal prices by encouraging competition. It is made up of research institutions, both international and within the USA, who pay a membership fee that goes to supporting 'high-quality, economical alternatives to high-priced journals.'

SPARC exists because 'the high and fast-rising cost of journals has had a devastating effect on the flow of scientific communication, the research community, and library collections. The situation is especially dire for journals in the scientific, technical and medical (STM) fields. SPARC was created to offer a constructive response to this issue.'

Rather than being a publisher, SPARC encourages and supports researchers and societies to create high-quality, low-cost journals—because Web-based journals have lower costs than print-based journals. It does this mainly through an advisory role, but to help these newly formed journals get off the ground, members of SPARC (i.e. libraries and institutions) are encouraged to subscribe to SPARC-endorsed journals, sometimes instead of a competing journal from a commercial publisher.

The revolutionary new approach

Online versions of printed journals represent the application of new technology to an old publishing system and business model. But a new medium enables one to question all the practices of the past. For instance, given that publishing on the Web means instantaneous access around the world, and greater opportunity for interaction with the readership, why have a printed version at all? Some readers may simply *prefer* flicking through a journal rather than staring at a computer screen, but can such preference justify the cost of printing, packaging, and distribution?

Journals online and in print

Doing away with printed journals entirely may be a little too radical for the medical profession at the moment. Print journals may also be online, but the paper version is not about to disappear. Conversely, most new online journals offer print versions—for now. For instance, the journal *Critical Care* is published bi-monthly but contains only a compendium of what is available on its Web site:

http://ccforum.com/

To demarcate this distinction the Web site has a slightly different name—the *Critical Care Forum.* Furthermore, because the main focus is the Web site, the publishers do not restrict themselves by having regular issues or publication dates; instead, the site is updated whenever articles are ready.

Journals online with some print

An example of a journal taking the next step is the *Journal of Medical Internet Research*. As well as the Web site there is a quarterly printed journal that contains only abstracts and short important articles:

http://www.jmir.org/

Online-only journals

BioMed Central, a major contributor of journals to PubMed Central (see above), is a commercial Web site without any printed presence whatsoever:

http://biomedcentral.com/

Like *Critical Care* (see above) it does not have regular issues or publication dates. Whenever a peer-reviewed article is ready it's published on the Web site (free for all to access). The Web site (see Fig. 2) has pages for original research in every area of biomedicine, and each of these is called a 'journal'. These, however, are not journals in the traditional sense of the word. They do not have a planned flow of content but instead are updated whenever a new article is published in that area.

More online journals are likely

In the past journals for specialist fields were not economically viable given their small subscription base. The relatively low costs of the Internet,

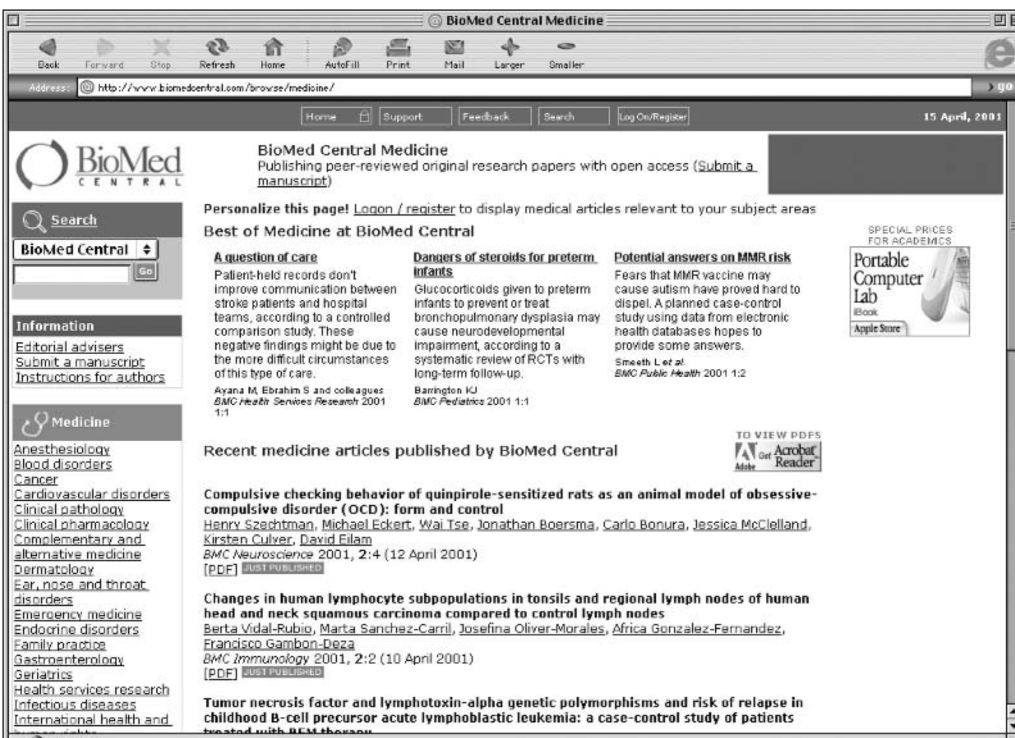

Fig. 2 BioMed Central reflects a new paradigm in online publishing, publishing articles as they are ready rather than according to a strict schedule.

however, now make it possible for these journals to survive and we can therefore expect to see more and more online journals in the near future. This is partly what SPARC base their goals upon (see above).

However, the prestige of authorship has always been more about *where* one is published as opposed to *what* is published. With that in mind, it remains to be seen how these journals will be received by the medical community.

Pre-prints and e-prints

A pre-print describes a research paper that has yet to go through peer review. If a pre-print is put on the Web it is called an e-print. The distinction between pre-prints and e-prints is rather blurred, mainly because we tend to see pre-prints only when they are posted on the Web, making them, by default, e-prints.

In some sciences, most notably physics, the circulation of pre-prints has been an accepted part of academic publishing and peer review for some time. E-prints developed as a natural extension of this pre-submission peer review, and physicists now routinely post their draft articles on an e-print archive called arXiv.org where colleagues can access the work and comment on it. The archive is operated by the Los Alamos National Library, which is funded by the US Department of Energy:

http://xxx.lanl.gov/

When the authors are happy that they have received sufficient comment, they revise the article and submit it to a journal for formal peer review and publication.

There is no such tradition of pre-prints among authors submitting to medical journals. Indeed medical journals have actively discouraged the practice, ostensibly to protect the public from non-peer-reviewed information, but also undoubtedly to protect the journals' exclusive scoops on research news. In particular the Ingelfinger rule (named after Franz Ingelfinger, a former editor of the *New England Journal of Medicine*) stipulated that the *NEJM* would not consider any article whose content had previously been widely circulated or mentioned in the press. As a result of this ruling (which other major medical journals adopted) the medical research community is cautious about non-peer-reviewed material and authors are guarded about their unpublished work. Although the Internet has made several major journals rethink their approach to the Ingelfinger rule, and several have launched e-print servers for posting non-peer-reviewed material [13,14], the uptake by authors has been slow.

Implications for peer review

All of this begs the question 'What role for peer review in the new environment?' Peer review has come to mean everything that happens to an article between submission to a journal and publication. It is the means by which the scientific community decides which articles should enter the public domain and in what form. For paper journals with limited space, this selection process is both a practical necessity and a means of developing prestige via the selection of only the best and most interesting articles. But peer review has been increasingly criticized for being highly subjective, prone to bias, easily abused, poor at detecting gross defects, and almost useless at detecting fraud [15].

As well as speeding up communication between reviewers and authors the Internet seems likely to transform the nature of peer review. First, the absence of space constraints means that editorial decisions need no longer be based on the journal's requirements and idiosyncrasies. For instance, a general medical journal need no longer worry about 'wasting pages' by publishing a paper that is relevant to only a small portion of its audience. Peer review can return to concentrating purely on the merits of the paper, making it less arbitrary and potentially less time consuming.

Second, the potential for greater interactivity between editors, authors, and reviewers means that peer review can shift from being a one-off event in an article's life to an ongoing process of comment and revision—which can begin even before a paper is submitted to a journal. Authors could post their protocols online to gather feedback on their proposed methodology; they could post their preliminary results to get advice on how to analyse the data; they could post the first draft of the paper for informal peer review, as in the Los Alamos model (see above); they could then revise their paper before sending it to a journal for 'formal' peer review; and finally, after the paper is published in a journal, they could revise their paper in view of the letters received by the journal or any new information. All this would, of course, create numerous versions of the same paper and even blur the definition of at what point a paper is published. These are both issues that the scientific publishing community is looking to address.

Finally, moves towards open peer review, in which the reviewers' signed reports are posted along with the published articles, offer the prospect of greater accountability and higher standards of ethical behaviour [16].

Open access

The lower costs of electronic dissemination have raised another major issue. Why should researchers give their work free to journals, volunteer their services as peer reviewers, and then buy the journals from publishers? Why, in effect, should the public pay twice for science—first to fund the research, and then to fund library subscriptions in order to access the results. To many people a system that made sense in a world of paper journals no longer makes sense in the online world. As the prices of journals soar and biomedical publishing becomes more of a monopoly [8], there is a growing feeling that the current publishing model has become more of a hindrance than a help to communication within science. Several alternatives now exist that offer free access to peer-reviewed research articles, including PubMed Central and BioMed Central (both described above).

The future of medical journals

Open access, online peer review, e-prints, and online-only journals are changing the way we process and communicate medical information. The Internet enables us to access databases of information that were previously either inaccessible or available solely in libraries. It also enables these databases to evolve from a source of references and abstracts to a fully searchable and comprehensive set of online full-text articles—all at the click of a mouse.

But if the research articles currently published in thousands of medical journals are eventually centralized into an accessible and searchable database, what role is there for medical journals? Granted, they offer peer review, but what if this evolves into a system of e-prints with continuous online reviews (see above)? Their role looks likely to move away from the publication of research articles, and to concentrate instead around the provision of reviews, commentaries, educational articles, discussion, and debate, helping to bridge the gap between research and clinical practice.

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7.2 Medical commerce

John Mack and Bruce McKenzie

Introduction

Electronic commerce (e-commerce) is the buying and selling of goods and services electronically—typically via the Internet. Broadly, e-commerce may involve business-to-business (B2B) or business-to-consumer (B2C) transactions. B2B data transactions are also known as electronic data interchange (EDI). Companies or organizations that engage in e-commerce are sometimes referred to as e-businesses, or 'dot coms' in reflection of the role of the Internet. The term 'e-health' is used to denote the application of e-commerce to healthcare, again typically using the Internet. More generally, e-health is also used to refer to any health-related activity on the Internet, overlapping with broader definitions of telemedicine (Chapter 3.3).

In this chapter we take a brief overview of how the Internet is being used to conduct medical commerce. We then focus on the online marketing and sale of pharmaceuticals as highlighting relevant regulatory and ethical issues of particular interest to the readers of this book.

E-health transactions

Outlining the process for implementing an e-health service is beyond the scope of this chapter. It is helpful, however, to gain some insight into the factors driving the adoption of e-commerce, and potential disadvantages of the e-business model (see Box 1). Whatever the transaction is for, making it securely is of paramount importance (see Box 2). For general information about how e-commerce works, see:

http://www.howstuffworks.com/ecommerce.htm

The true size of the e-health market is difficult to gauge, as estimates are widely discrepant. E-procurement—the 'buying side' of B2B e-commerce—has the potential to cover almost £10 billion per annum in goods and

Box 1 The e-health business case

Potential advantages may include:

- Reduced overheads (marketing, sales, support staff, etc.).
- Faster, more efficient automated transactions.
- Standardization of processes.
- A user-friendly Web interface.
- Healthcare consumer empowerment.
- Wider reach (around-the-clock access, global audience).
- Online product support (troubleshooting, technical help, etc.).

Potential disadvantages may include:

- Impersonal service.
- Unresolved regulatory issues.
- Concerns about transaction security (Box 2).
- Privacy and other ethical concerns (see text).

Box 2 Secure transactions

Although the risk of credit card fraud online may even be less than with giving details by phone or to a shop assistant, public perception often takes the opposite view. Mechanisms to secure Internet transactions (both financial and data) include password-protected access to Web sites, encryption (commonly using SSL—see p. 133) and 'digital certificate' authentication (p. 134). For more information about secure online shopping and banking, see:

http://home.netscape.com/security/basics/shopping.html

services purchased by the UK's National Health Service (NHS) alone [1]. Web-based systems supporting e-procurement (paperless requisitioning, ordering, and payment) are already in use in healthcare environments, such as Smartmission:

http://www.smartmission.com/

E-health does not, however, overlook individual professionals or consumers. In a broad sense, many of us have already experienced e-health firsthand. For example, we might use the Internet (and our credit card) to obtain:

- Travel tickets to a medical conference.
- Conference accommodation.

- Medical textbooks or equipment (see Fig. 1).
- Online journal subscriptions or document delivery services.
- Online consultations (see Chapter 3.3).
- Commercially sourced consumer health information (see Chapter 5.1).
- Personal medical insurance.
- Online pharmaceuticals (discussed below), etc.

Pharmaceutical companies and the Internet

Throughout product cycles, from research and development to marketing and sales, the pharmaceutical industry and its partners are using the Internet to accelerate drug development, improve efficiency by reducing costs, and enhance sales through online marketing and promotion (see Table 1).

Sponsorship of professional services

The pharmaceutical industry is very interested in reaching physicians online and supporting Internet use in their practices. By reaching key physicians and other health professionals that influence prescribing at an

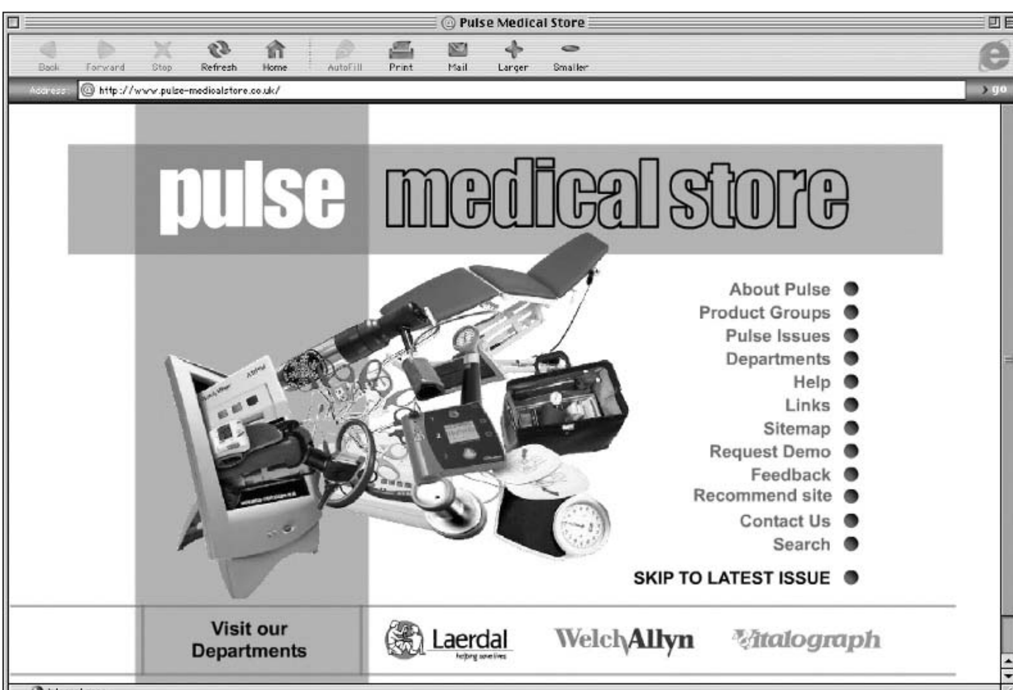

Fig. 1 Many of us make e-health transactions when we buy products online.

Table 1 Pharmaceutical industry Internet activity throughout a product life cycle

Product cycle step	Pharmaceutical company Internet activity
Research (drug discovery)	• E-procurement (buying products and service) • Scientific communications
Clinical trials (see also Chapter 6.3)	• Web-enabled clinical trial management • Investigator recruitment and communications • Subject recruitment
Pre-launch marketing	• Professional education
Launch	• E-advocacy programs, which utilize thought leaders in therapeutic categories and involve them in broadband online communications with targeted physicians to increase awareness of new products
Sales and marketing (growth phase)	• Direct-to-consumer product sites • Disease-specific Web sites (educating and empowering consumers) • Health-professional information • E-detailing (see text)
Sales and marketing (maturity phase)	• Online programs to increase patient compliance and persistence with products • Branding of company products and services • 'Solution branding' in which the brand is expanded to include online patient support features that engender loyalty to the brand even after the patent expires • Patient–physician communications regarding prescription refills, compliance issues, patient-reported outcomes, etc.

early point in the development cycle (i.e. before the approval stage), pharmaceutical companies can increase the awareness among physicians of their entry into a therapeutic category, and increase physician loyalty as the treatment moves into the marketplace. Financial support has been given to Internet portals to eliminate the cost of Web site subscriptions, to provide physicians with the capability to carry out e-commerce transactions with wholesalers, and to Web sites proffering continuing professional development (see Chapter 4.2).

E-detailing to physicians

The traditional means by which many health professionals learn about branded products is via the representative visit ('detailing'). The Internet is now being used to facilitate representative access to general practices in the UK:

Repcafe:
http://www.repcafe.com/

An emerging alternative to practice visits is e-detailing, the electronic delivery of product information, sometimes as part of an educational program. Doctors may prefer to request an e-detail in response to seeing pharmaceutical information on the Web, perhaps because it doesn't take time away from patients and is more convenient. A large proportion of marketing costs is spent on face-to-face detailing, and e-detailing is promoted as a cost-effective substitute. Example e-detailing sites are:

Physicians Interactive:
http://www.physinteractive.com/

E-detail for Xalatan (Pharmacia):
http://www.xalatan.com/health_pro/utility/e_detail.htm

Direct-to-consumer marketing

In the US pharmaceutical companies are permitted to promote their products directly to consumers. The Internet comprises a large audience of people who are actively seeking health information: over 45% of US Internet users have accessed health information in the past 12 months and there are about 30 million such health information seekers online [2]. The cost per prescription using the Internet has been estimated at $US14, versus $US220 for print and $US197 for television [2].

Pharmaceutical companies are providing much more than product labelling (package insert) information on the Internet. Direct-to-consumer (DTC) Web sites may include one or more of the following features:

- Basic product information.
- Full prescribing information.
- Balanced medical information relating to the product's indication.
- Frequently asked questions (FAQs).
- Games and other gimmicks designed to make the site 'sticky'.
- Targeted e-mail to keep consumers informed about updates to the site, provide information of interest to the consumer (such as daily pollen

counts), or remind patients to take their medication or refill their prescriptions.

- Contests, coupons, and rebates in exchange for marketing information collected via opt-in surveys (cutting out the telemarketing middleman to save costs).
- Questions to ask the doctor.
- Tools such as health risk calculators (e.g. for heart disease) and other health assessments.
- Compliance programs (refill reminders, self-help groups, drug management tools, etc.).
- Press releases.
- Links to professional information.
- Online communities (forums where patients can discuss experiences, side effects, etc.)

Note that many of these activities raise both regulatory and ethical (particularly privacy) concerns (see below).

Direct-to-consumer retail

For the consumer, online retail sales may offer convenience (especially for working persons or the house-bound), cost savings (e.g. not having to travel to a collection point), and relative anonymity (e.g. not having to consult a usual doctor or pharmacist). On the other hand, consumers may potentially face inflated charges or delays on delivery, missed drug interactions or contraindications, dosage errors, inadequate follow-up or monitoring for efficacy or adverse reactions, and counterfeit products. In some cases online sales may circumvent local prescribing policies or restrictions (e.g. a medicine licensed in one country may be unlicensed in another).

The UK's first online pharmacy service, Pharmacy2U, was launched in November 1999 (see Fig. 2). It offers (with trade association approval) sale and delivery of over-the-counter and pharmacy-only products, and the fulfilment and delivery of private or NHS prescriptions:

http://www.pharmacy2U.co.uk/

Drugstore.com is a similar US initiative:

http://www.drugstore.com/

Such initiatives are likely to become more commonplace. In September 2000, the UK Department of Health published *Pharmacy in the future* [3], promoting the exploration of 'e-pharmacy'—the electronic ordering and

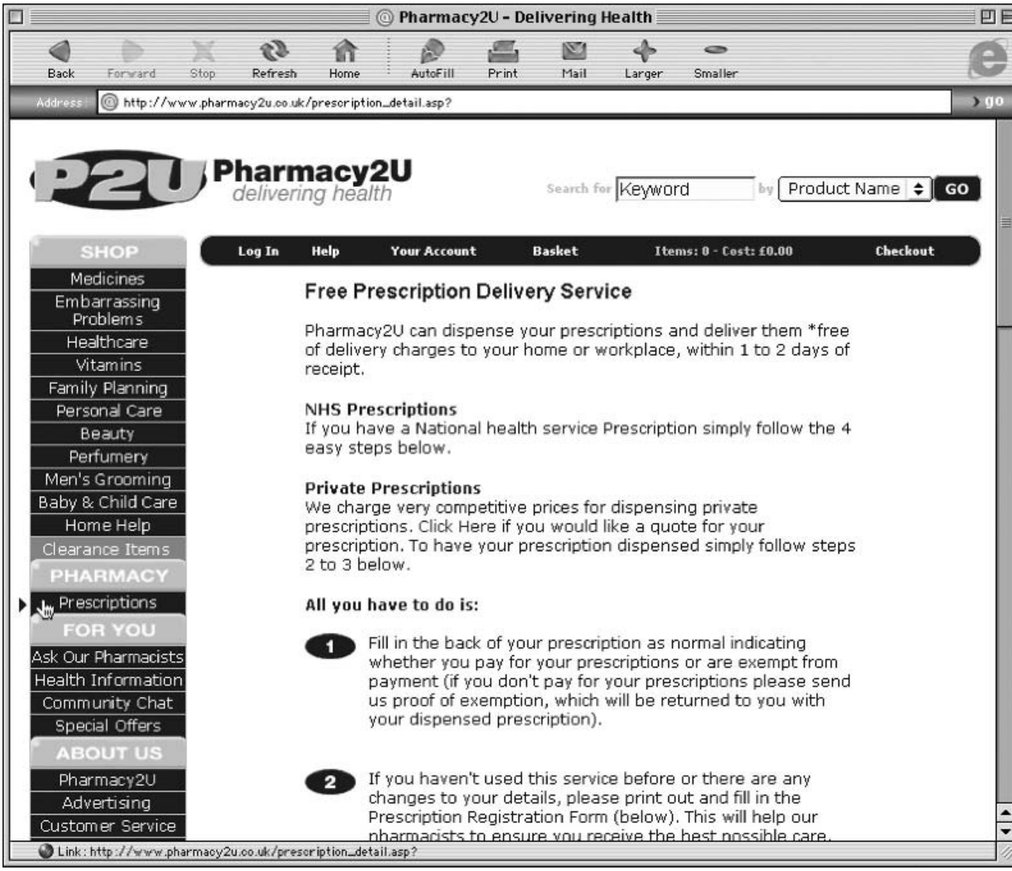

Fig. 2 DTC retailing of pharmaceuticals is established online.

dispensing of pharmacy-only (and eventually, prescription-only medicines):

http://www.doh.gov.uk/medicines.htm

Pilot projects evaluating the direct e-mail transmission of prescriptions from NHS general practitioners to community pharmacies ('e-prescribing') have been undertaken seeking, among other goals, to reduce prescription fraud and improve legibility.

Regulatory issues

Concern over potential harm arising from the advertising and sale of dubious unlicensed 'medicinal' products on the Internet has existed for some years [4]. The late 1990s saw interest in the increased Internet availability of licensed, prescription-only products, particularly of sildenafil. In one study, 45% of Web sites selling sildenafil did not require any kind of medical consultation. Where they did, no information about physician qualifications was available and many consultations were deficient [5]. Claims of actual harm resulting from Internet 'drug' sales have been reported [6,7], as have claims for the safety and effectiveness of Internet prescribing of selected medications—including sildenafil [8]. A new category of 'over-the-Internet' (OTI) drugs, safe enough to prescribe over the Internet but not over the pharmacy counter, has been proposed [9]. Such a category would force the medical profession to re-define what it considers to be an acceptable doctor–patient relationship.

As mentioned, DTC marketing is permitted in the US although many physicians (especially within the American Medical Association) are opposed to it, and there are rumblings in Congress to limit DTC advertising or to regulate it more closely. The border-ignorant Internet, however, allows non-US consumers to easily access pharmaceutical information intended for US citizens, and regulations in the rest of the world that restrict consumer access to this information are becoming unenforceable.

In the US both the Federal Trade Commission (FTC) and the Food and Drug Administration (FDA) regulate DTC advertising. The FTC focus on fraud and privacy issues and the FDA regulate every phase of the drug development and marketing cycle, including DTC advertising on the Internet as well as the sale and distribution of prescription drugs on and off the Internet.

In the UK (where DTC promotion is presently prohibited) the Medicines Control Agency (MCA) is the government body that licenses and monitors medicines on the UK market. The Advertising Standards Agency self- regulates general Internet advertising for UK-based sites, although the MCA and self-regulation by the trade association Code of Practice [10] also have a role in relation to medicines.

Regulatory issues around Internet advertising and sales are multiple and include:

- The logistics of multi-agency monitoring and enforcement responsibility.
- The limited jurisdiction of national agencies over foreign sites with a worldwide reach. Even the World Health Organization considered regulating the advertisement and sale of medical products on the Internet [11].
- The need to avoid harm. The US FDA publishes tips and warnings for consumers on its Web site. The FDA announced a crackdown on illegitimate Internet drug sales [12] and has proposed new legislation, the Internet Prescription Drug Sales Act of 2000 [13]. The MCA operate a special Internet Unit for the purpose of investigating cases of alleged breaches of medicines legislation arising from the Internet.

- Information not applicable to the local market. Most pharmaceutical company Web sites specify the intended audience.
- The need to counter misinformation. The UK trade association (the Association of the British Pharmaceutical Industry, or ABPI) hopes that the electronic Medicines Compendium (eMC), comprising summaries of product characteristics (SPCs) and patient information leaflets of UK-licensed medicines, will help address misinformation on the Internet (Press release dated Nov 19 1999).
- Addressing the presentation of biased or unbalanced information.
- The illegitimate sale of prescription-only medicines.
- The novelty of the Internet as a medium. The Royal Pharmaceutical Society of Great Britain has published guidelines for Internet pharmacies [14]. The US National Association of Boards of Pharmacy (NABP) initiated a Verified Internet Pharmacy Practice Sites (VIPPS) program.
- Difficulties in determining accountability due to the inherent characteristics of the Internet (e.g. discrete publishing, links between Web sites, the temporary nature of some sites, the ease of faking authenticity, etc.).

Internet resources for the above agencies and initiatives are given in Box 3.

Box 3 Internet resources of regulatory agencies

Medicines Control Agency:
http://www.mca.gov.uk/

Advertising Standards Agency:
http://www.asa.org.uk/

Association of the British Pharmaceutical Industry:
http://www.abpi.org.uk/

Buying medicines and medical products online (FDA):
http://www.fda.gov/oc/buyonline/

eMC (ABPI):
http://emc.vhn.net/

Royal Pharmaceutical Society of Great Britain:
http://www.rpsgb.org.uk/

National Association of Boards of Pharmacy VIPPS program:
http://www.nabp.net/

E-health ethics

Commercial online activities raise a number of ethical issues. These are succinctly encapsulated by the Internet Healthcare Coalition's eHealth Code of Ethics [15] under the principles of candour; honesty; quality; informed consent; privacy; professionalism in online healthcare; responsible partnering; and accountability (see Table 2). In relation to the Internet activities of pharmaceutical companies, it may be useful to consider each of these principles in turn. Note that the Hi-Ethics consortium has put a similar set of principles forward.

eHealth Code of Ethics (Internet Healthcare Coalition):
http://www.ihealthcoalition.org/

Internet Health Ethics (Hi-Ethics, Inc.):
http://www.hiethics.com/

Table 2 The eHealth Code of Ethics [15]

Principle	Responsibility
Candour	Disclose information that if known by consumers would likely affect consumers' understanding or use of the site or purchase or use of a product or service
Honesty	Be truthful and not deceptive
Quality	Provide health information that is accurate, easy to understand, and up to date Provide the information users need to make their own judgements about the health information, products, or services provided by the site
Informed consent	Respect users' right to determine whether or how their personal data may be collected, used, or shared
Privacy	Respect the obligation to protect users' privacy
Professionalism in online healthcare	Respect fundamental ethical obligations to patients and clients; inform and educate patients and clients about the limitations of online healthcare
Responsible partnering	Ensure that organizations and sites with which they affiliate are trustworthy
Accountability	Provide meaningful opportunity for users to give feedback to the site; monitor their compliance with the eHealth Code of Ethics

Candour

> People who use the Internet for health-related purposes need to be able to judge for themselves that the sites they visit and services they use are credible and trustworthy [15].

Web sites should disclose who owns a significant interest in the site and be open about the purpose of the site or service. Some pharmaceutical companies own non-branded disease-specific sites specifically designed to be reached by surfers looking for information about their medical condition and not necessarily about specific drug treatments. The non-branded site will, however, often be linked at many points to the branded drug site of the pharmaceutical company.

Honesty

> People who seek health information on the Internet need to know that products or services are described truthfully and that information they receive is not presented in a misleading way [15].

What pharmaceutical companies can say about their products on and off the Internet is strictly regulated by government agencies. Pharmaceutical company sites therefore generally comply with this ethical principle as a consequence of complying with the law. However, what they say on non-branded sites where no drug trade name is mentioned is not generally regulated by law, especially if they use independent expert opinion that is not controlled by the company.

Instances in which pharmaceutical companies use subtle techniques to mislead are not unknown, but this is not confined to the Internet. To protect themselves, consumers should always follow one of the most important tips from the Internet Healthcare Coalition: 'you shouldn't rely on just any one Internet site for all your health needs. … If possible, you should seek information from several sources and not rely on a single source of information.'

Quality

> To make wise decisions about their health care, people need and have the right to expect that sites will provide accurate, well-supported information and products and services of high quality [15].

Issues around the quality of health information online are considered further in Chapter 7.3.

Informed consent

> People who use the Internet for health-related reasons have the right to be informed that personal data may be gathered, and to choose whether they will allow their personal data to be collected and whether they will allow it to be used or shared. And they have a right to be able to choose, consent, and control when and how they actively engage in a commercial relationship [15].

Pharmaceutical companies, by law under most circumstances, must 'prominently' mention risks as well as benefits of their products. Risks should be displayed with the same size type and in the same location as benefits: you shouldn't have to scroll to the end of the page to find the risks mentioned in small type!

Privacy

> People who use the Internet for health-related reasons have the right to expect that personal data they provide will be kept confidential [15].

Reviewing Web site privacy policies of pharmaceutical companies reveals inconsistencies among policies of different pharmaceutical companies, and even between policies within the same company. Many policies do not meet minimum standards suggested by various ethics codes or by the FTC and the EU. Privacy is also considered in Chapter 3.4.

Professionalism in online healthcare

Health professionals will use the Internet increasingly to deliver care. Information itself, when presented by healthcare professionals, also can be considered care. Rather than establish new codes of ethics for the behaviour of health professionals on the Internet, the eHealth Code of Ethics specifies that existing professional codes be applied. However, the code does explicitly specify that online healthcare professionals should 'clearly and accurately describe the constraints of online diagnosis and treatment recommendations' and 'help "e-patients" understand when online consultation can and when it cannot and should not take the place of a face-to-face interaction with a healthcare provider.' Pharmaceutical companies that help physicians to use the Internet in their practices need, therefore, to be wary of the ethical consequences of their involvement.

Responsible partnering

> People need to be confident that organisations and individuals who operate on the Internet undertake to partner only with trustworthy individuals or organisations [15].

Many Internet-based companies are vying for pharmaceutical business to deliver solutions ranging from e-procurement to e-detailing. It is important for pharmaceutical companies to evaluate these partners not only from an economic point of view but also from an ethical point of view. Partners should pledge to comply with the same ethical standards adopted by the pharmaceutical company.

Accountability

The eHealth Code of Ethics' principle of accountability speaks about offering the means for consumers to provide feedback and to communicate with the party responsible for managing the site or service. It also specifies that sites 'review complaints from users promptly and respond in a timely and appropriate manner.'

Pharmaceutical companies do not have a great deal of experience with this kind of customer relationship management. They usually farm this out to fulfilment houses and call centres, which may be more interested in distributing marketing literature than being truly responsive to consumer inquiries.

Conclusion

E-health is an emerging development in the use of the Internet in healthcare. For many doctors and patients these developments are probably most evident in the online activities of pharmaceutical companies, who are incorporating the Internet into standard business processes and piloting projects evaluating the feasibility of various online business solutions. Such activities illustrate many interesting regulatory issues and ethical concerns, most of which may also be applied to other types of commercial online activity, whether medical or not.

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7.3 Information quality issues

Bruce McKenzie

Judgements about the 'quality' of an information resource can only be made with reference to a standard of some kind. Shades of quality (poor, average, high, etc.) form a comparative scale based upon the degree to which that standard is met. But how can we agree on the quality of something if we have no common standard by which to assess it? Herein lies one of the greatest challenges facing those using the Internet to seek out medical information. Although doctors also need educating in the skill of critically appraising medical information on the Internet (see Chapter 3.1), the focus of this chapter is on issues facing patients attempting to do the same.

What is quality?

The subjective nature of our scrutiny of information is neatly summarized by Delamothe: 'No omniscient detached observer exists who can simultaneously view an article through the eyes of a specialist researcher, doctor, patient, and member of the public, let alone take into account the different perspectives of orthodox and complementary medicine.' [1]. Quality is a multi-faceted thing; it means different things to different people as a function of the context in which information is presented and the requirements of the information user. A resource that lacks supportive 'evidence', such as a personal experience of illness [2], can still be valuable in other ways and so is not necessarily of poor quality. In most circumstances, however, one of the most valued aspects of quality in relation to healthcare information is accuracy.

Accuracy of content

While we may consider ourselves adept at subjectively determining the quality of a given resource, in truth we are only well placed to judge appropriately when we already have a detailed knowledge of the subject concerned. Paradoxically, information-seekers are ordinarily trying to acquire new knowledge—and are thus poorly placed to make judgements about the quality of the information they discover. When our own knowledge is not sufficient to enable us to make a judgement, we become reliant on indirect hallmarks of potential accuracy that tend to give the information weight.

Other factors

Thus, 'quality' describes more than merely the accuracy of medical content [3]. Several authors and groups have contributed to a daunting list of additional characteristics for quality information on the Internet. Although many different permutations are used, these characteristics include:

- Clear authorship, including author affiliations and qualifications [3–5].
- Medical advice given by appropriately trained persons [5,6].
- Information that supports existing doctor–patient relationships [5,6].
- Citation of original sources and balanced evidence [3–8].
- Disclosure of site purpose, ownership, sponsorship, and conflicts of interest [3–8].
- Dating of content [3–8].
- Useful, appropriate links and partnerships [3,4,6–9].
- Usability of the site, e.g. navigation, search engine, disability access, stated technology requirements [3,6–9].
- Provision for feedback or contact [3,5–7].
- Interactivity and use of appropriate media [3,9].
- Relevance to and use by the target audience [7,9].
- Use of a clear editorial review process [6–8].
- Separation of editorial, scientific, or educational content from advertising [4–6,8].
- Use of appropriate disclaimers, e.g. limitations of advice [6,7].
- Use of appropriate language, i.e. readability [6,8,9].
- Accessibility of the resource via search engines [9].
- Impact on users, clinical practice, and patient outcomes [9].
- Privacy and confidentiality of personal information respected [5,6,8].
- Restrictions (e.g. registration, payment) clearly stated [8].
- Provision of secure, efficient e-commerce transactions [8].

It is readily apparent that quality is difficult to define, ostensibly an entity without bounds that impinges on virtually every practical and ethical aspect of information provision. However, a review of published criteria (albeit in 1997–98) indicates some consensus on the importance of content, design, disclosure, currency, authority, ease of use, accessibility, and availability [10].

Why is quality an issue online?

Poor quality information is by no means the sole preserve of the Internet; printed patient education materials are often of poor quality (e.g. asthma leaflets [11]). On the Internet, however, the problem is magnified since anyone can become an information provider aided by the ease and low cost of publishing online [12]. The relative lack of individual accountability and the anonymity of the Internet also contribute to a Web littered with misinformation and unbalanced or unsubstantiated claims. Sometimes this misinformation is inadvertent; sometimes it is deliberate. Researchers have attempted to determine how rife the problem of misleading or incomplete information is in different disciplines. For example:

- Of 41 surveyed Web sites giving advice on the home management of febrile children, only 4 adhered closely to published guidelines [13].
- Of 50 Web sites found by searching the Internet for 'weight loss diets' only 3 confined themselves to sound dietary advice as given in published clinical guidelines [14].
- A search of 7 search engines looking for 'heavy periods' and 'patient information' found all the retrieved sites lacking when compared to quality criteria [15].
- Of 21 frequently accessed Web sites about depression, all scored poorly using three quality markers [16].

Quality assurance

The need to help patients find and utilize good quality information is recognized [17] and should be seen as a professional obligation. Such an obligation is consistent with the clinical governance agenda of the UK's National Health Service (NHS) [18]. Some kind of quality assurance for healthcare information on the Internet would therefore seem prudent. Eysenbach postulates that quality management depends upon four 'Es' [19], each of which we will consider in turn:

- Educating consumers to filter information.
- Encouraging self-regulation of health information providers (self-labelling).
- Evaluating information by third parties (third-party labelling).
- Enforcement, in the case of fraudulent or positively harmful information.

Teaching consumers appraisal skills

Do-it-yourself rating tools have been developed to help consumers identify good quality information (see Fig. 1). These tools typically make use of pre-defined quality criteria to present a time-consuming, self-scoring questionnaire or step-by-step checklist designed to filter out sites that

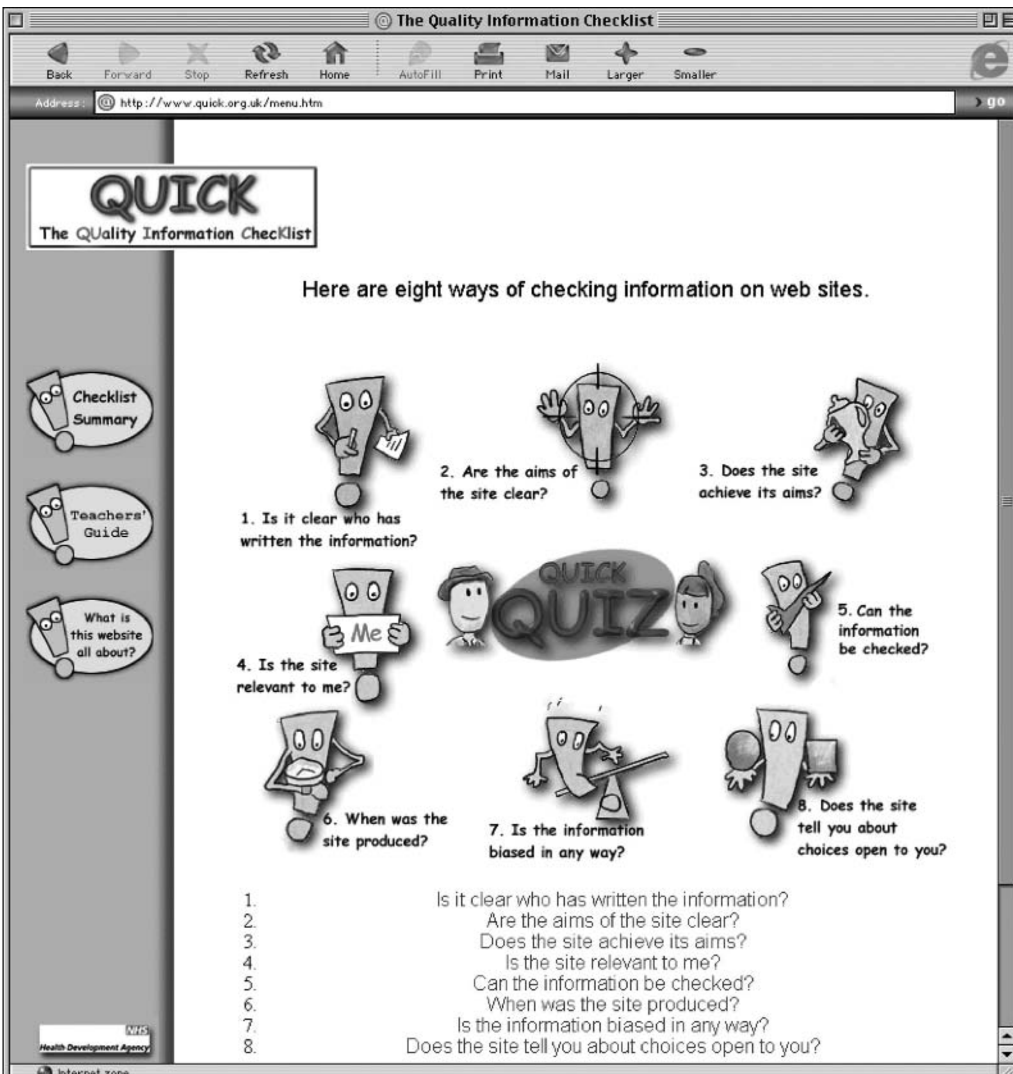

Fig. 1 The Quality Information Checklist is an easy-to-use tool that helps consumers filter out poor-quality healthcare information.

don't meet these criteria. For example:

The Quality Information Checklist (NHS Health Development Agency):
http://www.quick.org.uk/

Information Quality Tool (Mitretek Systems):
http://hitiweb.mitretek.org/iq/

The DISCERN Instrument (University of Oxford):
http://www.discern.org.uk/discern_instrument.htm

The Internet Healthcare Coalition offers tips for health consumers on finding quality health information on the Internet:
http://www.ihealthcoalition.org/content/tips.html

Provider self-labelling

The principal means of self-regulation is adherence to voluntary codes of practice. Quality is often a central theme to such codes and is one of the principles extolled by the broad-based eHealth Code of Ethics:
http://www.ihealthcoalition.org/

Other codes of practice, although voluntary and based on the provider's self-declaration, may require payment of fees or are subject to external validation and hence are forms of third-party labelling.

Third-party labelling

There are two broad ways in which third parties can label quality information: issuing kitemarks and providing portal sites. Both methods attempt to take the onus off the consumer by evaluating Internet content on their behalf, often using a rating system of varying complexity.

Kitemarks

The Kitemark of the British Standards Institution is a widely recognized symbol indicating quality and safety to UK consumers:
http://www.bsi-global.com/

Key to the Kitemark is independent testing and the ability to verify the right of an organization to use it. Similar kitemarks (seals, logos, badges, etc.) exist or are proposed for health information on the Web. These may indicate anything from agreement with a code of practice (as above) to a resource that has been independently and rigorously validated. One of the initial kitemarks to appear was the HONcode logo from the Health On the Net Foundation:

http://www.hon.ch/

The TEAC-Health project recommended the development of a 'EuroSeal' for Web sites that combined third-party assessment with adherence to a self-declared code of conduct [20]. Details of a site's accreditation would be downloaded in real time from the accrediting agency by clicking on the EuroSeal symbol. A very similar initiative is the MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net) project. MedCERTAIN combines an undertaking to abide by the eHealth Code of Ethics (see above) with a self- and third-party rating system to derive levels of trustworthiness for use by European consumers. The MedCERTAIN project relies on a metadata vocabulary (p. 206) to describe and evaluate Web page content:

http://www.medcertain.org/

The Which? Web Trader Scheme from the UK Consumer's Association sets out a code of practice for UK e-commerce Web sites and kitemarks some purveyors of health and beauty products:

http://whichwebtrader.which.net/

Hi-Ethics, Inc. (Health Internet Ethics) promotes a similar set of quality principles to the eHealth Code (see above), allowing US-based Web sites to pay for the privilege of accreditation and the right to display its e-Health Seal:

http://www.hiethics.org/

Advantages of kitemarking schemes may include:

- An indication to consumers that the site is approved.
- Kitemarked sites may be more likely to protect privacy and settle complaints.
- Self-labelling does not preclude freedom of expression (especially for alternative healthcare sites).
- Kitemarking is free to consumers and little time is required to verify kitemark authenticity.
- Schemes that employ ratings, levels, or categorization allow individual consumers to determine their own thresholds for content acceptability.

Disadvantages of kitemarking schemes may include:

- Too many competing schemes with different emphases may confuse consumers.
- Providers with 'logo-mania' may add to the confusion via multiple accreditations.

- The meaning of a kitemark may not be clear to consumers.
- Success depends on content provider acceptance and uptake.
- Very little content is currently kitemarked.
- Could be costly for providers, especially if it entails time-consuming expert review of their content.
- The stringency of kitemark validation is uncertain.
- Commercial or ethical pressure may cause providers to get kitemarked for the wrong reasons.
- Kitemarks may be misappropriated by information providers [19] and policing transgressors may prove difficult (see below).
- Schemes must accommodate local languages [21].
- Web site content is dynamic, necessitating regular review.

Portals

A portal is a Web site aiming to serve as a gateway to Internet resources. By becoming a preferred gateway, portal sites have the opportunity and the means to steer information seekers towards resources that they approve by virtue of linking to them. This is the approach taken by the US-based Healthfinder and the UK-based NHS Direct Online consumer portals:

Healthfinder (US Department of Health and Human Services):
http://www.healthfinder.gov/

NHS Direct Online (UK Department of Health):
http://www.nhsdirect.nhs.uk/

Some portal sites are geared toward both consumer and professional users, providing evaluations of the sites they link to and/or openly adopting a simple star rating scheme. For example:

OMNI (University of Nottingham):
http://omni.ac.uk/

Medical Matrix (Medical Matrix L.L.C.):
http://www.medmatrix.org/

Advantages of portals may include:

- They are often topic- or profession-focused, increasing relevance.
- Manual evaluations may be more reliable than general search engines.
- Browseable directories and in-site search engines may improve retrievability.
- There may be value-added features, e.g. home page personalization.
- Free to consumers.

- Portals that employ clear ratings allow individual consumers to determine their own thresholds for content acceptability.
- They represent an easy solution for novice users.

Disadvantages of portals may include:

- They cannot hope to cover more than a fraction of online content.
- Selection criteria are not always obvious and may be heavily biased (e.g. against alternative healthcare sites).
- Sites that use rating systems may overlook the users' context and needs [22].
- Success depends on consumer use of the portal site as users are not aware of ratings when accessing the site directly [23].
- Portals tend to come and go.
- Commercial partnerships and advertising-based business models used by portals may be off-putting.
- Rating systems are not interoperable and sometimes not applicable.
- Could be costly for providers, especially if it entails time-consuming expert review of their content.
- Web site content is dynamic, necessitating regular review.

Validating the validators

Evaluations are in general prone to asking the wrong questions, using the wrong methods, and wrongly interpreting the results [24]. Indeed, a review of instruments used to rate health information on the Web concluded that

> Many incompletely developed instruments to evaluate health information exist on the Internet. It is unclear, however, whether they should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm. [25]

Validating agencies may themselves be subject to review by information providers who take exception to unfavourable or defective ratings, so they need to be aware of the potential for legal challenge [26].

Dealing with transgressors

What do we do about those who do not comply with stated codes of practice, or misuse kitemarks? Although adherence to voluntary codes is not enforceable by law, the US Federal Trade Commission can act against companies failing to operate by declared standards [27]. In the UK the Office of Fair Trading supports self-regulation by trade associations:

http://www.oft.gov.uk/

Enforcement problems concerning the advertising and sale of dubious unlicensed 'medicinal' products on the Internet were discussed in Chapter 7.2. The European Union's Safer Internet Action Plan was launched in January 1999 and provides further insight into the legal and regulatory issues. It also promotes the use of telephone hotlines to report transgressions:

http://europa.eu.int/ISPO/iap/

Dedicated independent sites have also found a niche in bringing fraud and quackery to our attention. For example, Barrett's 'Quackwatch' site:

http://www.quackwatch.com/

Conclusion

Quality is hard to define in a meaningful way that fits all contexts. Although there are a number of efforts in progress to improve the quality of health information online, little real consensus exists as of this writing. Time will tell whether this can be achieved in the near future without another 'standards war', as typified by the early years of the Web. Translating any consensus on important quality attributes into a clear and easy-to-use tool for use by consumers is the next step [10]. Any solution must balance protecting patients with preserving freedom of expression; the World Health Organization's plan to control 'dot health' Web sites was rejected for this reason [28]. The Internet simply doesn't lend itself to top-down enforcement and it is certain that misinformation will not be stopped at its source. Whatever measures may lie around the corner, we must place accountability above all else.

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Conclusion

Bruce McKenzie

> The Orphan cried out in protest, as the cold of naked space entered his bones, 'Who am I?' And once more science answered. 'You are a changeling.' 'You are linked by a genetic chain to all the vertebrates. The thing that is you bears the still aching wounds of evolution in body and in brain. Your hands are made-over fins, your lungs come from a creature gasping in a swamp, your femur has been twisted upright. Your foot is a reworked climbing pad. You are a rag doll resewn from the skins of extinct animals. Long ago, 2 000 000 years perhaps, you were smaller, your brain was not so large. We are not confident that you could speak. Seventy million years before that you were an even smaller climbing creature known as a tupaiid. You were the size of a rat. You ate insects. Now you fly to the Moon.'
>
> Loren Eiseley, in *The cosmic orphan* [1]

The story of humankind is a one of an incredible journey, so dramatically told in this passage by Eiseley. Today, perhaps more than anything, it is our technological achievements that define us as a species, that make us unique. In modern society technological innovation continues our evolution with seemingly unstoppable momentum. So rapid is the pace of change that sociologists recognize 'future shock' [2] in those unprepared for it. Ill-prepared some of us may be for the Internet, but the rapidity of change is only a small part of the equation. Doctors are, after all, continually exposed to new developments throughout their increasingly technological careers and should, therefore, be able to adapt to Internet technologies with little effort or dread.

The problem is that doctors, being recalcitrant creatures, adapt only if they want to. And in order to want to adapt, they must first perceive a need. Some healthcare professionals do not perceive a need for the Internet. To them it is a toy, a novelty for those distracted from the true art of consulting with patients. They have no desire to use the Internet to enhance the practice of medicine in ways anticipated by those who advocate it. But medical use of the Internet has moved on in the last few years, and the voices of dissent are less conspicuous. The question no longer appears to be how we *could* use it, but rather how we *should* use it.

The visionaries among us put forward a notion of something that would revolutionize the way that we communicate, serve, learn, and even think about medical information. 'Revolutionize' is a strong and brusque word—it is perhaps better to gently evolve. The pages of this book have described the gentle evolution currently in progress. Our destination may not be clear, but one certainty is that medical practice will not be left to stagnate in the modern age of the network interface.

The need for medical use of the Internet can now be defined. The Internet's contribution to medicine is no longer mere potential. Rather, it offers the tangible inducements of efficiency, resource sharing, accessibility, knowledge procurement, consumer empowerment, and economy. The speed and convenience of electronic communications, and the ability to work together without meeting, attract us. We search for evidence and retrieve references without visiting a physical library, while patients employ a new avenue to consult us without visiting our place of practice. We anticipate around-the-clock access to clinical records from any location, while patients anticipate similar access to medical advice and information that enables them to take a more active role in their own healthcare. We learn in flexible ways using a global knowledge base, which in turn facilitates our contribution to shared understanding. We save trees, we save money, and we hope to save those lacking resources from information poverty. We seek to improve the practice of medicine and, ultimately, the delivery of healthcare. These are worthy incentives.

Evolution is never painless, however, and there are many challenges to be faced. Some we have identified within these pages. We are concerned about the confidentiality of private data, wary of the dangers of giving online advice to unseen (perhaps unreal) patients, and unnerved by other ethical questions. It remains far from easy to locate valuable and trustworthy resources despite promising but disparate attempts to address difficulties in information retrieval and quality assurance. Bandwidth congestion, brought about by the Internet's popularity, and unreliable computing systems all too frequently hamper our connections to the network. The battle for dominance in the software market has corrupted the 'universal experience' that underlay the conception of the Web, as volleys of new features that evolution necessitates lay waste to less capable computers. Much of the technology is bound to change before we have fully adapted. There is meagre evidence to support the positive influence of

Internet solutions on health outcomes (an attribute of information technology in general). Furthermore, doctors are accustomed to working in a regulated environment—most of what we do is measured against standards of one kind of another—but the Internet is quite dissimilar, being somewhat anarchic. All of these things conspire to make us shy away from the Internet as an everyday technology in medicine.

Nevertheless, it is not gradual natural selection that will ultimately determine the place of the Internet in medicine, but contemporary recognition of the need to adapt our practices to this technology. One of our contributors (AM) proposes a professional obligation for those of us acquainted with the Internet to 'give something back'. While this might take the form of adding information absent from the global database, it might also involve helping others to recognize the opportunities that the Internet offers. This book is but one such effort. We have endeavoured within these pages to illustrate what medical applications have been made of the Internet thus far and in so doing, deliver a glimpse of the future. We look forward to seeing you there.

Notes

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Glossary

It is well worth the effort of familiarizing yourself with terms in common usage. Without this familiarity, you will encounter many difficulties in understanding the language you will come across online, including that used by those whom you ask for help. Learning the language—like learning the Latin of gross anatomy—makes universal communication possible.

From the Preface to the first edition of *Medicine and the Internet* (1996)

56K modem See *V.90*.

A

ActiveX A technology from Microsoft that enables designers to embed small applications (ActiveX controls) into a Web page, similar to Java applets.

ADSL See *digital subscriber line*.

anonymous FTP Retrieval of a file from a public FTP archive using 'anonymous' as a user name, and an e-mail address as a password. See also *File Transfer Protocol*.

applet A small application (applet) written in the Java programming language and embedded into a Web page. Similar to ActiveX controls.

Archie An Internet service that assists in locating files available from public FTP sites, providing you know the name of the file to be retrieved.

asynchronous In telecommunications, this term is commonly used to indicate that an exchange of information involves a significant delay between the sending and receiving of that information (the alternative is real-time communication). In a more technical context, it refers to the transmission of information at a variable rate through a communications channel. See also *real time*.

authenticity In data security terms, an authentic message is one where the identity of the sender can be verified, often by means of a digital signature.

B

backbone A major or 'arterial' network connection, often long-distance, linking together a number of lower-bandwidth networks.

bandwidth In common usage, the capacity of a communications channel to transmit information. Modem connections to the Internet are low bandwidth (narrowband) relative to a high-bandwidth (broadband) ASDL connection, for example. Bandwidth is said to be 'congested' when many users are sharing the same communications channel, using up the available bandwidth.

bits per second (bps) A measure of the number of bits (the smallest unit of digital data) transferred per second over a communications channel. Modem speeds, measured in bps, are defined by modulation protocols.

bookmark A facility present in Web browsers allowing users to store and sort the URLs of Web sites they have visited. Also called 'Favorites'.

Boolean operator Also called a logical operator, used to define search criteria when using databases such as those indexed by MEDLINE. AND, NOT, and OR are Boolean operators, used in the form 'Find asthma NOT occupational'.

bps See *bits per second*.

broadband See *bandwidth*.

browser A synonym for a World Wide Web client. Refers to the casual ease that these clients bring to navigating the Internet.

C

cable modem A device that fulfils the role of a conventional modem, but instead of using telephone lines to transfer data, it uses cable television channels.

cache A reserved memory space on a computer for storing frequently required instructions, speeding its operation. Web browsers use a hard disk cache to store Web pages so they do not have to be repeatedly retrieved by the browser. See also *proxy server*.

cascading style sheets (CSS) See *style sheets*.

channel In a similar fashion to CB radio, Internet Relay Chat users hold conversations on particular 'channels'. So-called 'push' technology allows Web users to subscribe to broadcast ('Webcast') channels of automatically updated content, such as news headlines, instead of manually locating it. Channel content can be 'anchored' to the users desktop where updates are displayed at predefined intervals.

chat A facility present on the Internet as Internet Relay Chat or in some Web-based forums. Provides for the two-way exchange of messages as they are typed in real time, as opposed to e-mail which involves a lag between the sending and receiving of the message.

client A program that makes requests for the services of another computer, called a server. Each client works with a specific type of server or, as in the case of Web clients, several types of server.

conference A Web-based discussion area, newsgroup, or mailing list where users can hold 'virtual meetings' by reading and posting messages relating to a particular topic. Unlike chat, text-based conferences do not take place in real time.

confidentiality In data security terms, confidentiality implies that the contents of a message are visible only to the authorized recipient(s), and not to unauthorized persons who may intercept the message intentionally or inadvertently at any point in transit. Confidentiality is often preserved using encryption techniques.

cookie A small file left on your computer when you visit a Web site. When you return to that site the cookie identifies you as a unique visitor, using information stored within the cookie to set your personal preferences, remember passwords, gather data about your browsing habits, etc.

D

data compression protocol In relation to data transmission, a set of rules for reducing the size of a file on-the-fly so it can be transmitted in less time. Examples of protocols are MNP5 and V.42bis. See also *file compression*.

data integrity In data security terms, the retention of integrity implies that a message will pass unaltered over a communications channel, and that all attempts to breach confidentiality will be unsuccessful. When this is not the case, the data has lost its integrity.

digital signature authentication In data security terms, a common means of ensuring the authenticity of data. A unique digital signature appended to a data transmission is used to verify that the message is indeed from the stated sender.

digital subscriber line (DSL) Digital subscriber line connections access much of the unused bandwidth of ordinary telephone lines to provide an 'always on' Internet connection. 'Asynchronous' DSL (ADSL) is a flavour of DSL characterized by a difference in download/upload rates. A signal 'splitter' at either end of the connection allows for simultaneous data and voice/fax communications.

domain name The unique name of a computer on the Internet, comprised of several sub-domains that are used to group computers together. For example, all computers with uk in their domain name are located in the UK, but some of these will be located at National Health Service sites (…nhs.uk), and others on commercial premises (…co.uk), etc. See also *Internet Protocol address*.

download The process of retrieving a file from a remote host to your own computer over a communications link. See also *upload*.

E

e-health A term used to denote the application of e-commerce (buying and selling goods and services electronically) to healthcare, typically using the Internet. More generally, it is also used to refer to any health-related activity on the Internet, overlapping with broader definitions of telemedicine.

electronic mail (e-mail) Messages delivered over an electronic network (such as the Internet) to an electronic mailbox where they can be read, saved to disk, and/or replied to. See also *mailing list*, *newsgroup*.

e-mail See *electronic mail*.

encoding A technique used by e-mail software for sending binary (non-text) files over the Internet as e-mail attachments. See also *Multipurpose Internet Mail Extensions (MIME)*.

encryption See *public-key cryptography*.

error-correction protocol In relation to data transmission, a set of rules negotiated by modems to ensure that a transmitted file is received intact (i.e. without error). Example protocols are MNP4 and V.42.

Ethernet A standard for local-area networking (hardware, protocol, and cables).

eXtensible HyperText Markup Language (XHTML) A redefinition of HTML as an application of XML, XHTML continues to convey human-readable information on the Web. It can be combined with machine-readable data in XML format. See also *metadata*.

eXtensible Markup Language (XML) Using a syntax like HTML to tag individual bits of information, XML results in documents that are machine-readable. Unlike HTML, XML focuses on meaning rather than document structure, thus facilitating electronic data interchange.

eXtensible Stylesheet Language (XSL) See *style sheets*.

extranet Part of an intranet that is available to restricted users outside the immediate organization itself, e.g. via a password-restricted Web page on the Internet.

F

FAQ See *frequently asked questions*.

Favorites See *bookmarks*.

file compression Using special compression software, most computer files can be made smaller so that they take less time to transfer and occupy less storage space. Compressed files are denoted by a characteristic file suffix, and must be expanded before they can be used. See also *data compression protocol*.

file suffix An acronym forming part of the file name, typically comprising 2–4 characters, and indicating the type of file or program necessary to expand or decode it (e.g. .ZIP, .GIF). See also *file compression*.

File Transfer Protocol (FTP) Part of the TCP/IP protocol suite used on the Internet for transferring files across TCP/IP connections. Files that are available by FTP are commonly held in public archives on FTP sites. See also *anonymous FTP*.

firewall A secure gateway protecting an internal network (such as an intranet) or individual computer from unauthorized access. Firewalls may comprise software and/or hardware barriers.

flame A harmful or derogatory response to a mailing list or newsgroup item that the recipient considers offensive. A 'flame war' is the online equivalent of a heated argument.

form A feature of some Web pages. Fill-out forms contain elements that allow the user to send data such as a password or search term to the host computer. Filling out a form may involve entering text, checking boxes, or using pull-down menus and buttons. Browsers that support this facility are said to be 'forms compatible'.

frame A feature on some Web sites that divides the browser window into separate areas (frames), each displaying a different HTML file. Often one unchanging frame contains links for navigating around a Web site, while the content of other frames changes to display the content of the Web site.

free software Software made available for anyone to use, copy, and distribute with or without making modifications (therefore requiring the source code—the instructions for building a program). This type of licensing arrangement is broadly referred to as 'open source', although there are other flavours of free licence. See also freeware.

freeware An ill-defined term sometimes used for gratis software that cannot legally be modified and is not distributed with source code, so is not considered 'free'. See also free software.

frequently asked questions (FAQ) Originating in Usenet newsgroups, an FAQ is a file serving to answer questions commonly asked by new users, or merely to record information about a particular subject that has been collated for the benefit of others. Many FAQs are now available on the World Wide Web.

FTP See File Transfer Protocol.

G

gateway A communications link between two different kinds of network. Serves to convert information into a compatible format before it can be passed on to an adjoining network. Many networks that are not connected directly to the Internet use a gateway to enable e-mail exchange with Internet users.

GIF See Graphics Interchange Format.

Gopher An Internet service pre-dating the Web that organizes information on the Internet into a series of hierarchical menus. Information on Gopher services can be accessed with a Gopher client, or more commonly, via your Web browser. See also Veronica.

Graphics Interchange Format (GIF) A common graphics file format used extensively in World Wide Web pages. An animated GIF is a special GIF format that incorporates several distinct images into the one file. Web browsers display each image in sequence after a specified delay, producing the appearance of an animation. See also Portable Network Graphics.

H

helper application An external application needed by your Web browser to provide functionality not contained within the client, such as the ability to play back a movie file or act as a Telnet client. See also *plug-in*.

home page The default hypertext page to be loaded by a Web client when it is first launched or when the user clicks the 'Home' button. Also the top-level (entry) page of any Web site.

host Refers to a computer on a network that provides services to many users. Dial-up users connect to the Internet via a host computer maintained by their service provider. Host computers often run server software with which users interact by means of a client.

HTML See *HyperText Markup Language*.

HTTP See *HyperText Transport Protocol*.

hyperlink A contraction of 'hypertext link', a connection (link) between elements on Web pages (text, images, etc.) that you click on with a mouse.

hypertext A document containing links to other documents. The reader is not forced to read a hypertext document from beginning to end, but can freely follow any one of several marked links to associated material. Hypermedia, a superset of hypertext, implies that other media such as graphics, sounds, and animations can lead to or be the result of clicking on a link. The Web uses the metaphor of a hypertext 'page'.

HyperText Markup Language (HTML) A special syntax used on the Web to structure hypertext documents or pages. An ordinary text document can be 'marked-up' (e.g. <h1>Heading</h1>), which tells the Web browser how to interpret the enclosed text.

HyperText Transport Protocol (HTTP) The protocol used to transfer hypertext pages between a World Wide Web server and client.

I

image map A graphic within a Web page that contains a number of 'hot spots'. Clicking on one of these spots with the mouse typically changes the page contents, as happens when clicking on a text-based hypertext link.

IMAP4 See *Internet Message Access Protocol*.

Integrated Services Digital Network (ISDN) A digital telephone line that achieves data transmission rates beyond that of a conventional modem by sending the data as a stream of bits, rather than converting it to sound for transmission as does a modem.

Internet A worldwide network of networks that communicate using the TCP/IP protocol suite. See also *Transmission Control Protocol/Internet Protocol*.

Internet dialler Software supplied by a service provider or as an operating system add-on that is used to manage SLIP or PPP configuration, other dial-up settings, connection/disconnection, and sometimes provides menu access to a range of Internet clients.

Internet Explorer A popular Web browser. See also *Netscape*.

Internet Message Access Protocol version 4rev1 (IMAP4) An alternative protocol to POP3 for receiving e-mail, proposed as an Internet standard, and optimized for those needing to manage their e-mail from multiple locations and/or devices. See also *Post Office Protocol*.

Internet Protocol (IP) address A unique identifying number assigned to every computer directly connected to the Internet. Comprised of a grouping of four numbers separated by full stops, it corresponds to an easier-to-remember domain name.

Internet Relay Chat (IRC) A 'chat' facility on the Internet allowing users to communicate with each other on various topic-based channels via real-time typing. Newer IRC clients provide graphical 'virtual environments' in which users are represented by a virtual persona sometimes called an 'avatar'.

Internet service provider (ISP) An organization or company from which you rent access to the Internet. ISPs selling dial-up access typically use Points of Presence (PoPs—banks of modems) that provide local access to the ISP's high-speed IP network, which itself is part of the wider Internet.

Internet services A collective term for applications available over the Internet. Primary tools are electronic mail, File Transfer Protocol, and Telnet. Later-generation tools, such as Archie, Gopher, Wide Area Information Servers, and the World Wide Web, build on these basic applications. Usenet is not strictly an Internet service; see also *network news*.

Internet telephony With special software, a microphone, speakers, and a sound card for digitizing speech, Internet users can converse with each other online. Sometimes called 'voice over IP' (VoIP). Although sound quality is less than that of an ordinary telephone, the system provides intercontinental communications for the cost of a local call to your service provider.

intranet A private computer network set up to share resources and exchange messages based on Internet technologies (TCP/IP protocols, Web browsers, etc.). It may be linked to the Internet itself via a secure firewall that typically protects sensitive internal information from outside access. See also *firewall*.

IP address See *Internet Protocol (IP) address*.

IRC See *Internet Relay Chat*.

ISDN See *Integrated Services Digital Network*.

ISP See *Internet service provider*.

J

JANET See *Joint Academic NETwork*.

Java A programming language from Sun Microsystems that can be used to write small applications (applets) that are downloaded and run by Java-aware Web browsers. See also *ActiveX*, *JavaScript*.

JavaScript A scripting language from Netscape based on Java that is simpler to learn than the full Java programming language. JavaScripts are embedded directly within HTML and primarily used to make Web pages more interactive. See also *Java*.

Joint Academic NETwork (JANET) A network linking UK universities, colleges, and research establishments. Originally using the X.25 protocol, it is now based on TCP/IP. Several 'SuperJANET' projects have focused on increasing the capacity (bandwidth) and reach of the network.

Joint Photographic Experts Group (JPEG) A graphics file format in common use on the Internet. Although JPEG files can contain more colours than GIF files, the file compression technique used to keep the file size down causes some loss of data and therefore degrades the sharpness of the image. See also *Graphics Interchange Format*, *Portable Network Graphics*.

JPEG See *Joint Photographic Experts Group*.

K

KB See *kilobyte*.

kilobyte (KB) A measure of computer memory or disk space, equal to 1024 bytes (i.e. 2 to the power of 10). See also *megabyte*.

L

LAN See *local area network*.

leased line An expensive, typically high-speed, constant connection to the Internet that is leased from an Internet service provider or telephone company.

list owner A person responsible for maintaining, and perhaps moderating, a mailing list.

list server A program that manages e-mail messages. Most list servers are used to manage mailing lists; others have a role in sending files from FTP archives by e-mail, for example.

local area network (LAN) A network of computers physically located on the same premises, or within a relatively small geographic area. See also *wide area network*.

M

mailing list A list of e-mail addresses used by a list server to automatically distribute messages relating to a particular topic to persons on the list. See also *moderation*.

MB See *megabyte*.

Medical Subject Headings (MeSH) A hierarchical classification system developed by the US National Library of Medicine, used to map a user's search terms to those indexed in MEDLINE.

MEDLINE The largest biomedical bibliographic database, produced by the US National Library of Medicine and available free on the Internet.

megabyte (MB) A measure of computer memory or disk space, equal to 1 048 576 bytes (i.e. 2 to the power of 20)—roughly a thousand kilobytes. See also *kilobyte*.

MeSH See *Medical Subject Headings*.

metadata Machine-readable identifiers that describe something about the documents containing them, such as key words. This 'data about data' is commonly referred to as metadata.

MIME See *Multi-purpose Internet Mail Extensions*.

mirror A mirror site replicates the directory structure and file content of another site, such as an FTP archive or set of Web pages. Mirrors serve to increase the number of users that can have simultaneous access to particular resources, and help reduce bandwidth congestion on certain parts of the Internet. Access to a 'local' mirror is typically faster than to one on another continent, for example.

modem A device (software or hardware) allowing computers to communicate using telephone lines. A modem works by converting digital information into analogue sound for transmission (MOdulation), which is converted back into digital information by the receiving modem (DEModulation).

moderation The role of a person who screens postings to mailing lists and online forums, including newsgroups, to ensure that they are appropriate to the stated aims of the discussion.

Multipurpose Internet Mail Extensions (MIME) A standard for the encoding of binary (non-text) files so that they can be sent via e-mail. MIME content types, a special line of text within MIME files, tell programs that recognize MIME about the type of encoded file (e.g. movie, graphic, etc.).

N

narrowband See *bandwidth*.

netiquette A code of appropriate behaviour, or 'network etiquette', expected of all users when posting messages to newsgroups.

Netscape A popular Web browser. See also *Internet Explorer*.

network The linking together of computers and/or their peripherals (such as printers) to enable resources to be shared, or to foster communication between the users of those computers. See also *local area network*, *wide area network*.

network news A collective term for Internet newsgroups propagated using the Network News Transfer Protocol. Although Usenet newsgroups are propagated in this way on the Internet, they are propagated using different protocols over other networks making up Usenet.

Network News Transfer Protocol (NNTP) The protocol used on the Internet to exchange network news.

newsgroup A collection of e-mail messages relating to a certain topic or topics on the Internet and Usenet, arranged into a hierarchical naming system. An example of a newsgroup is sci.med.

news reader A client used on the Internet to read and post newsgroup articles via NNTP.

news server A computer running software that enables a news reader to retrieve newsgroup articles using NNTP.

NHSnet A wide area network for the UK's National Health Service. A one-way gateway enables NHSnet users to explore the Web and exchange e-mail with Internet users. NHSnet has its own NHS-specific Web pages (NHSweb), protected from outside access by a firewall.

NNTP See *Network News Transfer Protocol*.

O

offline The state of being disconnected from the Internet. See also *online*.

online The act of connecting to ('going online') or state of being connected to the Internet. See also *offline*.

open-source software See *free software*.

P

path name A description of the location of a file on a storage device such as an FTP archive, Web site, or hard disk. On the Internet, uniform resource locators (URLs) use a path name to specify the directory location and/or file name of a particular resource.

PDF See *Portable Document Format*.

plug-in Add-on modules that turn your Web browser into a versatile multimedia player, enabling it to play/display a variety of file formats seamlessly from within the browser itself. See also *helper application*.

PNG See *Portable Network Graphics*.

Point of Presence (PoP) A bank of modems supplied by an Internet service provider, often permitting access to their high-speed TCP/IP network by way of a local call.

Point to Point Protocol (PPP) A network interface that allows dial-up users to temporarily connect their computers to the Internet and use TCP/IP-based clients. It is generally preferred to the older alternative, SLIP. See also *Serial Line Internet Protocol*.

PoP See *Point of Presence*.

POP See *Post Office Protocol*.

Portable Document Format (PDF) A *de facto* standard for electronic document publishing, popular because it preserves the look of the original document (unlike HTML) which can then be viewed on different computer platforms. PDFs can be viewed and printed with the gratis Acrobat Reader program.

Portable Network Graphics (PNG) Developed to replace GIF and JPEG as the graphic file format of choice on the World Wide Web. See also *Graphics Interchange Format*, *Joint Photographic Experts Group*.

portal A Web site aiming to serve as a gateway to Internet resources. A number of portals are targeted at doctors. Portal home pages are increasingly personalized for individual visitors; see also *cookie*.

Post Office Protocol (POP) A protocol used on the Internet for storing and retrieving e-mail, currently in its third version, i.e. POP3. See also *SMTP*, *Internet Message Access Protocol*.

PPP See *Point to Point Protocol*.

proxy server Refers to a server acting as a secure gateway between an internal network and the wider Internet. Incoming and outgoing requests made by clients must pass through the server. Alternatively, it refers to a disk cache on the Internet for storing frequently accessed Web pages. Specifying a proxy in this instance usually helps conserve bandwidth on intercontinental communications links, and can result in a quicker response to client requests.

public domain A category of software where the author does not exercise copyright. Such software may be modified without permission.

public-key cryptography A common method of encryption—the encoding or enciphering of data to preserve its confidentiality and integrity. The public-key system uses two software 'keys'—one public, to encrypt a message, and one private, used by the recipient to decode it. A digital signature is often included as part of an encrypted message to indicate authenticity.

R

real time In telecommunications, interaction between two or more computers/users occurring without a significant time lag. For example, users of Internet Relay Chat communicate in real-time typing—a line of text is visible to the recipient virtually the moment it is sent. See also *asynchronous*.

Request for comments (RFC) A document used on the Internet to record descriptions of evolving protocols and standards.

RFC See *Request for comments*.

routers Devices on the Internet and other networks that send information from one network to another.

S

search engine A program that looks for information in response to a query made by a user. A number of search engines have been developed to help locate files on the Internet, some of which specialize in finding medical resources.

Serial Line Internet Protocol (SLIP) A network interface that allows dial-up users to temporarily connect their computer to the Internet and use TCP/IP-based clients. It is an older standard than the more popular alternative, PPP. See also *Point to Point Protocol*.

server Refers to either a host running 'server' software (as in 'servant'), or to the software itself. A server directs the sharing of resources among many users on a multi-user host, and fulfils requests made by client software (or, in some cases, by e-mail).

shareware A category of software that users can try out for a specified evaluation period before buying it, as required by the terms of a user license. An extremely popular method of distributing software via the Internet. See also *free software*.

Simple Mail Transport Protocol (SMTP) The main protocol used on the Internet for sending and receiving e-mail.

SLIP See *Serial Line Internet Protocol*.

SMTP See *Simple Mail Transport Protocol*.

spam Unwanted and unsolicited e-mail, usually containing advertising.

streaming The playback of a file, such as audio or video, during downloading as a 'stream' of data as it flows from computer to computer (as opposed to waiting until the entire file has been retrieved before starting playback).

style sheets Cascading style sheets (CSS) separate presentation-orientated tags from the tags determining structure in HTML documents, making it easier for Web site designers to change the look of their site simply by altering the style sheet. eXtensible Stylesheet Language (XSL) serves a similar function for XML documents.

SuperJANET See *Joint Academic NETwork*.

T

table A feature of some Web pages. Information can be tabulated using certain HTML tags that describe rows and columns. More often, however, these tags are used by Web page designers to create more interesting page layouts. In the later case, the data cells making up the table are often invisible.

TCP/IP See *Transmission Control Protocol/Internet Protocol*.

telemedicine Broadly, the use of telecommunications technologies and computers to overcome barriers in healthcare such as physical distance. In practice telemedicine can describe any medical activity (e.g. teaching, administration, etc.), although is popularly seen as enabling doctors to provide a 'virtual presence' from a remote location, as in a doctor–patient or generalist–specialist consultation. It is considered by some to be a subset of e-health. See also *e-health*.

Telnet The name of a protocol forming part of the TCP/IP protocol suite used on the Internet. Also an Internet service, where a Telnet client emulates a 'virtual Internet terminal' allowing remote access to a host computer.

threading Message threading refers to the ability of a conference message reader or news reader to automate a user's ability to 'follow a thread'. That is, to read all the messages in a particular conversation in the sequence in which they were posted, rather than a chronological sequence of individual messages pertaining to many conversations posted to the conference or newsgroup.

Transmission Control Protocol/Internet Protocol (TCP/IP) A protocol suite including Transmission Control Protocol, Internet Protocol, SMTP, FTP, Telnet, and many other protocols operating on the Internet.

U

UMLS See *Unified Medical Language System*.

Unified Medical Language System (UMLS) A classification system developed by the US National Library of Medicine. The UMLS Metathesaurus contains information about medical terms and their co-occurrence in MeSH and other thesauri, enabling MEDLINE searches to be conducted using the vocabulary most familiar to the searcher.

uniform resource locator (URL) A standardized syntax used on the Internet describing the location and method of accessing Internet resources. Each URL is composed of several elements: the type of Internet service, the domain name of the host, the port address, and the path name.

upload The process of sending a file from your own computer to a remote host over a communications link. See also *download*.

URL See *uniform resource locator*.

user A generic term for anybody who operates a computer for any purpose.

user name Some Internet hosts require each user to identify him or herself with a user name (or user ID) on that system. This is often used in association with a password.

Usenet A global conferencing system where messages pertaining to particular subjects are distributed in the form of newsgroups over the Internet and many other networks. Although it is most often described as one, Usenet is not strictly an Internet service because it doesn't rely on TCP/IP-based networks for message distribution.

V

V.90 A modulation protocol enabling compliant modems to download data at speeds up to 56 000 bps ('56K') prior to the application of compression protocols (uploads are restricted to 33 600 bps).

Veronica The name of a search engine which locates objects indexed by Gopher, such as a keyword in a menu or document title.

videoconferencing Telecommunications between two or more people using a video signal to transmit images and audio in real time.

virtual private network (VPN) Blurring the divide between public and private networks, a virtual private network uses a 'tunnelling protocol' and encryption to send private data through public networks such as the Internet.

virus A small segment of software code created by a malicious prankster that 'infects' a computer, causing it to behave strangely or to lose data. Virus-detection software can scan for unusual activity that might be caused by a virus. Viruses can be transmitted by e-mail, contained within a file attachment (which must then be run on the recipient's computer to cause damage).

voice over IP (VoIP) See *Internet telephony*.

VPN See *virtual private network*.

W

WAIS See *Wide Area Information Servers*.

WAN See *wide area network*.

Wide Area Information Servers (WAIS) A server that supports client access to a database indexing the full contents of documents pertaining to a certain topic. Searches are composed in plain English, and 'relevance feedback' is used to identify documents that best fit the search criteria.

wide area network (WAN) A network of computers, or a network of networks, not physically located in the same small geographic area. See also *local area network*.

wild card A character such as an asterisk used to stand in for an uncertain or variable character or characters in a search string. For example, 'Find cardio*' would include cardiology, cardiopathy, cardiogram, etc.

World Wide Web (WWW) An extremely popular Internet service using the metaphor of a page, each associated via hypertext links with other pages widely distributed over the Internet. Readers of Web pages—which may include graphics and other multimedia elements—use a browser to navigate this 'web' of links in any order that they choose. See also *HyperText Markup Language*, *HyperText Transport Protocol*.

WWW See *World Wide Web*.

X

XHTML See *eXtensible HyperText Markup Language*.

XML See *eXtensible Markup Language*.

XSL See *eXtensible Stylesheet Language*.

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