The internet is the world’s largest information source. And it is still growing rapidly – by 20 million new pages a month according to some estimates. Internet usage is also increasing. It was estimated that 140 million people were using this resource in 1996. Last year, that number had grown to an estimated 605 million (NUA Internet Surveys, 2003). One of its functions is to be a source of information for patients wanting to know more about their illnesses.

Before the invention of the internet, patients who wanted to find out more about their disease would be confined to wading through heavyweight medical books or incomprehensible research papers. Even then, access was limited as few patients had membership rights to the specialist libraries containing these sources.

In less than a decade, however, there have been radical changes in the spread of information. From their own homes patients can now find information on practically any disease, although it is primarily accessed by younger and middle-aged patients. Older people are more likely to still see the doctor or specialist nurse as their primary source of information.

Range of information Information on the internet varies from specialised research papers to more populist sites with medical and health information. Another huge area is the self-help and support sites, many of which include anecdotal information and personal stories.

Cancer is particularly well served, with a huge range of organisations and individuals providing websites. Typing the word cancer into Google, the popular search engine, yields about 17.7 million results.

Martin Ledwick, senior cancer information nurse for CancerBACUP, thinks the web can be extremely useful and it is good for patients to have a range of information sources to help them understand their situation. However, there are concerns about the quality of some information.

‘Anyone can put information on the internet, so not all medical information has been checked,’ he says.

Another problem is that scientific papers generally apply to the group of people in the research study – probably with tightly defined criteria for acceptance, such as a particular cancer at a certain stage. The results may not apply to all patients with the same cancer, so can be hard to interpret.

‘We would encourage patients who are looking for information on the net to check what they have read with their cancer specialist, cancer nurse or GP. Or patients can ring the CancerBACUP helpline, which is staffed by nurse specialists who can help make sense of what they have found,’ says Mr Ledwick.

Quality of information The quality of information on the internet is a concern of the Consumers’ Association. Its recent report, Patient Information: What’s the Prognosis? (2003) evaluates a number of sources, including over 20,000 UK health-related internet sites. The report reveals that these sites are often contradictory and not always reliable.

The CA is asking for the NHS Information Standards Board to work with existing kite-marking agencies to develop an agreed code and system of accreditation.

The Health on the Net Foundation has set up a code of conduct for providers of medical or health information and advice (Box 1). Reputable health sites subscribe to the eight-principle code, which aims to improve the reliability and credibility of information on the internet.

Helping patients Jenny Wood, head of information resources at the Lynda Jackson Macmillan Centre for Cancer Support and Information in West Hertfordshire, has spoken to many patients who have gathered reams of information on their cancer from the internet, and has developed a strategy for helping them.

‘As a starting point I ask the patient to set aside the information they have come with and ask them to backtrack. I need to find out more about their story, what treatment they are having, what they know already.

‘Then I focus on their worries and their concerns to find out why they ended up searching the web. The search is often prompted by a particular anxiety. It may be, for example, that we have failed to give them some information that they need and we can then try to remedy that. Otherwise we can talk specifically about the information they found, focusing on their concerns.’

Misinformation Ms Wood says patients sometimes find information about treatments that are not yet available or may never be available. Misinformation interferes with communication with patients. She explains: ‘It is difficult to get people to disengage from information they have obtained. The nurse then has a double job. She or he has to tell the patient that the information they have found on the net is not right or is inappropriate, and then to explain that their needs may be better served by another source of information.

Another area of difficulty is when patients read another patient’s personal story on the web. If it is negative and apportions blame, the patient can end up worrying that their treatment has not been right.

Ms Wood says when nurses give out information leaflets, they can explain the contents and be sure they are relevant, appropriate and at the right level. They can also check that the information has been understood.
Ms Wood says: ‘Ten years ago patients didn’t always realise they were allowed to know what drugs they were taking. But when information is available people want more of it. What we can do is help patients access good quality information on reputable sites and be there to try and answer their questions.’

Leaflets at the Lynda Jackson centre are categorised with a ‘traffic light’ system. Green information is suitable for all, orange is more specific and not suitable for all patients. Red information, such as clinical trials, carries a vast and useful US site.

A range of publications for members, but also a searchable directory of hospices, which is free to all.

For further information on the code visit: www.hon.ch/HONcode

BOX 1. HEALTH ON THE NET FOUNDATION’S CODE OF CONDUCT FOR HEALTH WEBSITES

- Medical or health advice will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organisation.
- Information provided is designed to support, not replace, the relationship that exists between a patient and his or her doctor.
- Confidentiality of data relating to individual patients and visitors to a medical/health website, including their identity, should be respected.
- Where appropriate, information on a site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified should be clearly displayed.
- Any claims relating to the benefits or performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence as above.
- A site will seek to provide information in the clearest possible manner and provide contact addresses for visitors who seek further information or support.
- Support for a site will be clearly identified, including the identities of commercial and non-commercial organisations that have contributed funding, services or material.
- If advertising is a source of funding it will be clearly stated. The advertising policy will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

BOX 2. USEFUL CANCER WEBSITES

**GENERAL**

- Cancer Research UK: www.cancerresearchuk.org
- Resources for health professionals and a link to their site for patients and families, CancerHelp UK.
- Macmillan Cancer Relief: www.macmillan.org.uk
- Contains sections for health professionals and patients/carers, including a directory of quality checked information materials for people with cancer.
- Department of Health Cancer Homepage: www.doh.gov.uk/cancer
- Links to key government documents and sites, including The NHS Cancer Plan.
- CancerBACUP: www.cancerbacup.org.uk
- Contains a searchable database of organisations, support groups and sources of help, a list of UK cancer guidelines, a clinical trials search page, and a health professionals ‘microsite’. CancerBACUP’s publications are available for download.
- OMNI: http://omni.ac.uk
- Gateway to quality-checked health websites, and an internet tutorial for nurses. About 200 links to cancer sites.
- National Electronic Library for Health: www.necl.org.uk
- Links to many resources including free clinical evidence and Cochrane Library. Includes National Electronic Library for Cancers at www.necl.org.uk
- CancerNet: www.cancernet.co.uk
- Factsheets on a range of issues for patients.
- A vast and useful US site.
- Mount Vernon Cancer Centre: www.mountvernononcancercentre.nhs.uk
- For patients and carers. Good patient information leaflets.
- Hospice information: www.hospiceinformation.info
- A range of publications for members, but also a searchable directory of hospices, which is free to all.

**SPECIFIC CANCERS**

- Breast Cancer Care: www.breastcancercare.org.uk
- British Lymphoma Society: www.lymphoedema.org/bls/select.asp
- Colon Cancer Concern: www.coloncancer.org.uk
- International Myeloma Foundation UK: www.myeloma.org.uk
- Leukaemia Research Fund: www.lrf.org.uk
- Lymphoma Association: www.lymphoma.org.uk
- Oesophageal Patients’ Association: www.opa.org.uk
- Prostate Cancer Charity: www.prostate-cancer.org.uk

**ACTION CANCER NORTHERN IRELAND**

- www.actioncancer.org
- Support and services for people living in Northern Ireland.

**TENOVUS**

- www.tenovus.com
- Research and support charity based in Wales.