



THE INTERNET AND PATIENT INFORMATION

Although the internet has only been around for a relatively short period of time, its influence on both clinicians and patients alike is growing rapidly. **Carol Bond**, Senior Lecturer in Health Informatics at Bournemouth University, examines the internet and its relationship with patient information.

I find it hard to talk about the internet historically as, although it often feels as if it's been around for ever, it's only been available to the public for the last 20 years. The Office of National Statistics didn't start asking about internet use in the General Household Survey until 2000, when only a third of households had home access to the internet. Amongst students starting pre-registration nurse education at a university in the south of England that year only 41 per cent had year round access to a

computer with an internet connection.

In the intervening 10 years not only has internet availability changed enormously, with 93 per cent of students having a computer and internet connection, the internet itself has also changed considerably. It has developed from being a mainly static information-giving medium to a dynamic, interactive communication tool.

In spite of the high level of computer ownership amongst nursing students,

nurses have been slow adopters of IT, seeing computers as something that gets in the way of patient care rather than something that supports it. A recent clinical nurse lead for the Connecting for Health programme is quoted as saying 'if articles are branded as IT it's unlikely that nurses will pick them up, let alone engage with them.'

As patients turn to the internet, however, they might lead a change in this attitude. At the moment many nurses don't



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Research undertaken with online breast cancer support groups found that only 0.22 per cent of posts contained wrong or misleading information and that other contributors corrected this within an average of four and a half hours.

Various attempts at establishing some type of quality kitemark for health websites have been made. The most enduring is Honcode, and the NHS has attempted to introduce its own schemes. The NHS's most recent attempt is the Information Standard, however this is expensive to obtain and the number of organisations that are listed on the website as having signed up are small.

People looking for online health information have been found to have poor awareness of these quality marks and the schemes have been criticised for being of limited use to the lay end user.

Online health information users

The concern about self diagnosis is not borne out by research; many users of online health information are seeking to better understand a health problem they, or a family member, have. Rather than seeking to self diagnose, people living with long-term conditions tend to use information found on the internet to help them prepare for consultations.

They are very supportive of the NHS drive to see people living with long-term conditions as active participants in their own care, working in partnership with professionals rather than being passive recipients of care. Online health information users have the expectation that their use of online resources will improve their interaction with healthcare professionals.

The healthcare field, however, is struggling to keep up with the leading edge patients. Two factors considered in most quality schemes are the authority of the site and the evidence base of information. When considering interactive web 2.0 sites, however, where peers are sharing information, the authority is that of someone living with a condition and the evidence base is their experience, which may include significant co-morbidities which condition-specific sites often struggle to deal with.

The question of what constitutes good quality information is also open to debate, especially as research has found that many patients using online health

information were seeking points of view not associated with mainstream medical thinking.

Patients rating GPs

The internet is developing so quickly that it is difficult to know what its patients (and health care professionals) want from it and from health services. Some attempts to encourage patient participation haven't been well received by the medical community, such as the ability for patients to rate their GPs on the NHS Choices website. Patients don't appear to particularly want this facility either. Checking my local area, half of the closest 20 GP practices haven't been rated at all. The most rated practice only has three ratings. With such low levels of participation the ratings and comments are in danger of lacking balance.

It is also worth questioning if the NHS should play a general role in patient information or if it should focus on ensuring that patients are aware of what they are entitled to under NHS care. The internet does not operate within country boundaries and it is easy for patients to find out about treatment options in other countries, which opens practical and ethical problems that need discussion.

Defining informatics

As Paula Procter says in her report from IMIA NI on page 16 in this edition, information systems in healthcare tend to underpin financial management. Certainly in the NHS in recent years, the focus has been on the development of large scale computer systems. IMIA NI's definition of nursing informatics (agreed in 2009) is wider than this narrow technology focus:

'Nursing informatics science and practice integrates nursing, its information and knowledge and their management with information and communication technologies to promote the health of people, families and communities world wide.'

Perhaps for too long the focus has been on the T in IT rather than the I. Instead of talking about IT – information technology – we need to make a subtle shift and talk about information and technology. Patients deserve healthcare professionals who understand their information needs and work with them in a new relationship that acknowledges that professionals are no longer the sole source of that information.

understand enough about the internet and its role in patient information to be able to work effectively with their patients.

Historically health professionals have been concerned about patient use of online health information. Two worries are around the quality of the information being assessed, and that patients will use it to self diagnose. The worry around the quality of health websites is to some extent justified.

Research undertaken

Whilst there are undoubtedly some poor quality websites in existence, research into cancer-related websites found a low incidence of inaccurate information.

