

The informed patient: friend or foe?

Like the use of the internet, the informed patient is a growing phenomenon. In this article, **Marjorie Weiss** looks at how pharmacists can deal with them

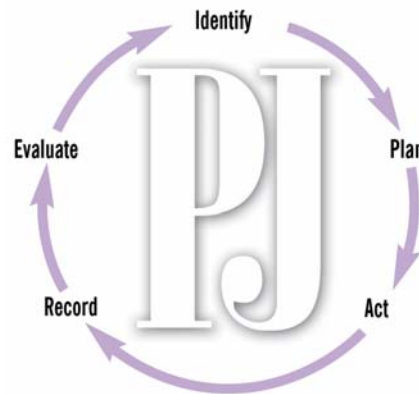


Health care professionals need to recognise that patients want more information

Although GPs remain a common source of health information for patients, people also use a range of other sources, such as the internet, leaflets, books, newspapers and magazines, nurses, pharmacists, family and friends. The changing attitude towards patients within the UK health care system — illustrated by Government initiatives, such as the Expert Patients Programme — and the increased access to information (eg, on the world wide web) have made it easier for patients to take more responsibility for their health and have prompted them to ask more questions.

It is estimated that 32 per cent of Europeans and 53 per cent of Americans search the internet for health information, with websites becoming as important as non-internet sources for health information.¹ This knowledgeable patient-consumer, the “informed patient”, has become a fact of modern life and, given that younger people are more likely to access the internet than older people, this phenomenon is unlikely to diminish in the coming decades. Health care professionals need to recognise that patients want more information and are prepared to search for it.²

Marjorie C. Weiss, DPhil, MRPharmS, is a senior lecturer in pharmacy practice at the department of pharmacy and pharmacology, University of Bath



Identify knowledge gaps

1. How do you deal with an informed patient?
2. What are the key criteria for judging the quality of information on the internet?
3. List three good quality health-related websites on the internet.

Before reading on, think about how this article may help you to do your job better. The Royal Pharmaceutical Society's areas of competence for pharmacists are listed in “Plan and record”, (available at: www.rpsgb.org/education). This article relates to “working with information” (see appendix 4 of “Plan and record”).

Motivations and perceptions

Patients seek health information for a variety of reasons, including a desire to find out what is wrong, wanting to learn more about a specific clinical condition or treatment, to help with self-care or to decide when it would be appropriate to consult a health care professional.

After seeing a health professional, people can also search for information as a way of reassuring themselves that they know all that is available: to ascertain the veracity of what they have been told or to find out about treatment options that may not have been covered in the consultation. This checking on information may be more likely if a patient is dissatisfied with a consultation. Research suggests that when accessing information on the internet, patients seek out websites aimed at health care professionals because they want to have access to more complex information.³

Health care professionals may not always view a patient coming to see them, loaded with information from family, friends or the internet, with complete equanimity. Some may feel threatened by an informed patient, perceiving that their professional knowledge is being challenged by someone who, for whatever reason, has felt the need to access information traditionally kept within the domain

Panel 1: Tips for dealing with an informed patient

(1) Be honest if you do not know the answer

If the question or topic is something you do not have a clue about, be honest about it. However, you could read through the material with the patient and make a professional judgement.

(2) Listen to the patient

Let patients tell their story as to what information they feel they need and why they need it. For example, were they worrying about something specific? Had they tried to get this information from any other sources? What difficulties had they had in getting the information they needed? Ask them what is concerning them and from what they found out, what they think the answers are. In truth, their perceived answers are probably what is concerning them.

(3) Manage your time

You might not be able to give advice immediately. If you are short of time, ask the patient to come back when you are less busy. You might also need time to look at the information properly. If the information is conflicting between different sources, you will need to identify the more accurate one and this can also take time.

(4) Help the patient to identify good internet sources

Ask patients to show you where they have sourced their information and indicate which of these sources are reliable and which are not.

(5) Be wary of everything that is available on the internet

Explain that some information is published on the web can be one-sided. Just as we are advised not to purchase goods from sites without the "padlock", the recognised symbol for trusted sites where money is exchanged for goods, not all health-related websites are trustworthy.

of the practitioner. Health care professionals also have concerns about the accuracy of information from non-professional sources, particularly with regard to the quality of information available on the internet. Moreover, they may believe that some patients do not have the ability to understand complex medical information.

Time is a crucial concern for pharmacists. Time to discuss the information with a patient is needed as well as for the professional to access information themselves (online or otherwise) during a busy working week.

So, if an informed customer visits a pharmacy, seeking the pharmacist's opinion or advice, how could the pharmacist deal with the situation? To try to answer this question, several experienced pharmacists were asked how they would handle an encounter with an informed patient who has accessed information from the internet. Their tips are shown in Panel 1.



Pharmacists can help patients develop their skills as critical users of health information websites

Even if a patient's concern is completely irrational from a pharmacological perspective, it is important to uncover it and acknowledge his or her view

A discussion of how to handle such an interaction using a specific clinical example follows. Although this article chiefly focuses on information accessed from the internet, the overall strategy for dealing with an informed patient and many of the principles for judging the quality of health information can be applied to many situations regardless of the source of health information.

The interaction

A regular customer, Samantha Jones, comes into your pharmacy clutching a sheaf of papers which, she says, is all about Femodene — the new GP in the local surgery has prescribed it for her. From searching on the internet, she has found that Femodene can cause blood clotting. You dispensed the pills to her a few days ago but she is thinking "maybe I should stop taking them". There are two basic steps to the consultation:

- Gather information
- Provide additional information or reassure as appropriate

Gather information The first stage in dealing with an informed patient is to listen fully and find out what prompted him or her to look up the information. Was Ms Jones worried about something in particular? Was she dissatisfied with her consultation with the new GP? Her answers to such questions should reveal why she thinks she is particularly at risk of a blood clot (ie, what her additional risk factors are) and what she knows about why she was prescribed Femodene.

You find out that Ms Jones's work involves considerable travelling and she is concerned that her frequent air travel, in conjunction with the Femodene, puts her at increased risk of getting a blood clot. Ms Jones does not know why she was prescribed Femodene on this occasion; she has used other oral contraceptives in the past.

Treat concerns or ideas seriously Ms Jones is clearly concerned about her risk of having a blood clot. Looking at the information she has collected will help you understand her concerns. A frequent cause of failure in communication between a health care professional and a patient is when a patient feels that his or her views have been devalued or dismissed, or that the health professional has failed to understand his or her perspective.

In this case, Ms Jones's anxiety about having a blood clot, even though the risk is small, is a legitimate issue for an individual taking an oral contraceptive to be concerned about. However, even if the concern was completely irrational from a pharmacological perspective, it would be important to uncover it and acknowledge the patient's viewpoint.

Inform or reassure as appropriate

From your own knowledge, or after consulting your own internet sources (see Panel 2), you can reassure Ms Jones as to the relative risks of thromboembolism when taking

Femodene compared with traditional second generation oral contraceptives (25 v 15 cases per 100,000 women per year of use) and compared with the risk of thromboembolism in pregnancy (60 cases per 100,000 pregnancies).

Information about the risks of third generation oral contraceptives can be found in the British National Formulary and the Bandolier website. The NHS Direct website provides useful advice on the risks of thromboembolism associated with long-haul air travel, as well as useful strategies for prevention. This website discusses the uncertainty regarding our current state of knowledge concerning long-haul air travel and thromboembolism (eg, that it is not known whether the flight itself causes the thrombosis or whether people who have a thrombosis after air travel were at risk for other reasons). This uncertainty should be conveyed to the patient underlining an inherent feature of much clinical information: not all of it provides definitive black and white answers and medical knowledge is always evolving. The uncertainty around current evidence needs to be communicated to the patient.

This may also be a good opportunity to make Ms Jones aware of the variation in quality of information on the internet so she can develop her own skills as a critical user of health information websites. The Health on the Net (HON) Foundation has developed a code of conduct which describes eight key ethical principles that website producers should abide by when presenting health care information:⁴

- Authority — the website indicates the qualifications of authors
- Complementariness — the information presented should support, not replace the doctor-patient relationship
- Privacy — the website owner should respect the privacy and confidentiality of personal data submitted to the site by the visitor
- Attribution — the website should cite the source(s) of published information, date and medical and health pages
- Justifiability — the website must back up claims relating to benefit and performance
- Transparency — the website should include identities of editor and webmaster, and the editor should be accessible (eg, an accurate e-mail contact is provided)
- Financial disclosure — the website should identify funding sources
- Sponsorship — the website should clearly differentiate between advertising and editorial content

Health-related websites are under no obligation to incorporate these key principles but may display the HONcode logo which, when accessed, will indicate whether the site is still endorsed by the HON. Taking this one stage further, a recent UK project called Judge Health provides detailed advice for consumers on how to search the internet for

Panel 2: Some useful websites to use or recommend

<http://medguides.medicines.org.uk>

Medicine Guides provide information about medicines as part of the UK Medicines Information Project. The website contains information on medicines for a range of conditions, such as diabetes, cardiovascular medicines and depression.

www.patient.co.uk

A collaboration between two GPs and EMIS, a developer of general practice computing systems, this website provides comprehensive information on health and disease, aimed at the UK general public.

www.besttreatments.co.uk/btuk/home.jsp

This website presents clinical evidence for patients from the *BMJ* and provides information on conditions and treatments, decision support and operations and tests.

www.prodigy.nhs.uk

Prodigy provides computerised decision support to GPs. Parts of the website include clinical guidelines for practice and patient information leaflets for a variety of conditions and drugs.

www.library.nhs.uk/Default.aspx

The UK National Library for Health aims to provide up-to-date knowledge and support to guide clinical decisions. It is aimed at UK health professionals but can be accessed by the public.

www.nlm.nih.gov/medlineplus

Medline Plus covers topics on health and drugs and provides access to a medical encyclopaedia. The website was developed by the US National Library of Medicine and the National Institutes of Health.

www.nhsdirect.nhs.uk

The NHS Direct website contains a health encyclopaedia, information on treatments and a self-help guide, as well as local information about the NHS.

www.jr2.ox.ac.uk/bandolier/index.html

Bandolier is an on-line journal, developed in Oxford, providing evidence-based information about UK health care.

www.guideline.gov

The website for the national guideline clearinghouse is an American resource for evidence-based clinical practice guidelines.

www.sign.ac.uk

The Scottish Intercollegiate Guidelines Network website aims to improve the quality of health care for patients in Scotland through the development and dissemination of national clinical guidelines based upon best current evidence.

www.mayoclinic.com

The US Mayo Clinic's website supplies medical information for patients. It includes sections on diseases and conditions, specific drugs and healthy living, and various health decision guides.

health information, how to judge the quality of a website and how to manage information in partnership with health care professionals.⁵ This site was developed by the Information Research Management Research Institute at Northumbria University in partnership with the charity Contact a Family. The Judge Health project's consumer guidelines were developed to help consumers make informed decisions about websites (see Panel 3, p146).

Acting as an internet guide

When dealing with an informed patient, there are several options for how to provide infor-

Panel 3: How to judge the quality of a website⁵

Issues that should be considered in order to judge the quality of a health-related website include:

- **Trust and reputation** Is the website reputable and trustworthy?
- **Identity** Who or what organisation produced the site?
- **Purpose** What are the website's aims and who is its audience?
- **Funding sources** Who funds the site?
- **Date** When was the site last updated or reviewed?
- **Bias** How is the information written — is a balanced view provided?
- **Accuracy** Who wrote descriptions of conditions and treatments and what sources did they use?
- **Medical research** How is complex medical research explained?
- **Personal experiences** Are personal experiences clearly marked as personal?
- **Foreign sites** Different health systems may have different terms or health care practices
- **Communication** Can the website owner be contacted easily?
- **Links** Why and how have links been chosen?
- **Disclaimers** What are the site's terms and conditions and are issues, such as privacy, copyright and accuracy of information, covered?
- **Kitemarks** Is the site endorsed by another organisation?
- **Design** Is personal information private and secure? Are advertisements clearly marked? Is the website it easy to use?
- **Interactive facilities** Are there e-mail lists, bulletin boards, chat rooms? If so, what are the required rules for polite, supportive behaviour?

mation. It can be presented verbally to the patient from the pharmacist's own knowledge, or it may be possible for the pharmacist and patient to access the sites together in the pharmacy. A third possibility is for the pharmacist to access the internet first and present the information to the patient at a later time.

Finding appropriate, high quality information which is of relevance to the patient's concerns does take time. As noted by one pharmacist (Panel 1), do not be afraid to arrange a appointment with the patient at a future time so you can read the information properly. Another option is for the pharmacist to be the patient's "internet guide" by making him or her aware of the quality issues in internet health information and suggesting useful websites that can be accessed alone. Whatever approach is taken, it is important for pharmacists to identify the pharmacy profession as a useful resource for health information.

This role of internet guide may be particularly appropriate if you are approached by a friend or family member in an informal or social situation for advice about medicines or a condition. One strategy for managing such situations is to empower patients to access appropriate information themselves before seeing their doctor.

These situations can be particularly problematic because you are unlikely to have access to all the medical or pharmaceutical information about the patient and, in situations where there may have been poor communication between the patient and a professional colleague, you would not wish to judge another professional without having full information.

The situation may mean that the individual needs to be referred to his or her GP. As an internet guide, the pharmacist could encourage the person to prepare a list of questions to ask the GP at the appointment.

Conclusion

Pharmacists have a choice in how to manage an encounter with an informed patient and, based on the roles identified by McMullan,² there are three potential approaches. The "professional in control" approach is where the pharmacist insists on the "rightness" of his or her professional knowledge as being superior to information available on the internet, discouraging the patient from accessing information other than through the conduit of a health care professional.

The "collaborator" is when the pharmacist works with the patient to trawl through the information and evaluate the veracity and appropriateness of the information in partnership with the patient.

The final approach is for the pharmacist to be an internet guide, directing patients to reliable and clear information, giving them the skills to recognise good quality sites and providing them with recognised internet sources which provide high quality reliable advice. Although this might appear to be "giving away" professional wisdom to patients, it firmly identifies the pharmacist as a resource for high quality patient information to which patients will be likely to return in the future.

References

1. Reuters. Consumer-targeted internet investment: online strategies to improve patient care and product positioning. Reuters Business Insight Report; May 2003.
2. McMullan M. Patients using the internet to obtain health information: how this affects the patient-health professional relationship. *Patient Education and Counselling* 2006;63:24-8.
3. Boyer C, Provost M, Baujard V. Highlights on the 8th HON survey of health and medical internet users. Geneva: Health on the Net Foundation; 2002.
4. The health on the net code of conduct for medical and health websites. Available at: www.hon.ch/HONcode/Conduct.html (accessed 1 December 2006).
5. The Judge project for judging the quality of health information on websites. Available at: www.judgehealth.org.uk/consumer_guidelines.htm (accessed 1 December 2006).

Action: practice points

Reading is only one way to undertake CPD and the Society will expect to see various approaches in a pharmacist's CPD portfolio.

1. Visit some of the websites in Panel 2 and judge for yourself how useful these websites are to your practice.
2. Use the criteria in Panel 3 to evaluate the quality of your favourite health-related website.
3. Try incorporating some of the techniques suggested in this article (eg, focusing on the patient's perspective) the next time an informed patient visits your pharmacy.

Evaluate

For your work to be presented as CPD, you need to evaluate your reading and any other activities. Answer the following questions: What have you learnt? How has it added value to your practice? (Have you applied this learning or had any feedback?) What will you do now and how will this be achieved?