

Knowledgeshare

Web alert: finding high-quality patient information resources online

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Introduction

Providing written information to patients about healthy living, medical conditions, treatment options and self-care not only benefits the individuals concerned but can reduce the burden on healthcare providers. From the individual's point of view, it can be difficult during a consultation for patients to absorb verbal information, only around 10% is remembered on average,¹ and understanding the terminology used can also be a challenge. The main role that healthcare literature plays, according to a 2004 survey of patients, is 'explaining what the doctor has said in plain language'.² It has been shown that patients' understanding of their illness can be enhanced when advice from general practitioners (GPs) is backed up by written patient information.³

Taking the wider view it is apparent that, as the population ages, information for patients on managing their own long-term conditions will help to limit the impact on healthcare staff and budgets. Since the publication of *Better Information, Better Choices, Better Health* three years ago,⁴ the Department of Health has pushed for a better-informed public who will take responsibility for their lifestyle and healthcare choices. To this end, the concept of an 'information prescription' was introduced, in order to raise the importance of information provision in the patient consultation. These prescriptions should be specific to individual patients, aimed at directing people to relevant books, leaflets, websites and support groups to help them to manage their own condition.

Of course, most primary care staff already provide education and information to patients, and over half of the population already relies on information from their GP or local pharmacy. Unfortunately, the quality of such information is variable.⁵ Stylistic issues,

content issues, and readability of the text all need to be taken into account, and recommendations should be based on the best available evidence from systematic research. A number of schemes have been developed to guide producers of patient information towards producing the most helpful, accessible materials, and some of these will be discussed below. Aside from this there are many collections of health literature available online, some more reliable than others. This article highlights a few of the most useful.

Patient UK: www.patient.co.uk

The aim of Patient UK is to provide the public in the UK with good-quality information about health and disease. The authors – Dr Tim Kenny and Dr Beverley Kenny, GPs in Tyne and Wear – do this by writing evidence-based information leaflets on a wide range of medical and health topics. They also review health- and illness-related websites and link to many of these from an online directory. UK sites are the primary links although there are some links to selected overseas sites. The website is divided up into sections, including 'Health and disease leaflets', 'Support organisations', a 'Directory of websites' and 'All about medicines'.

You can browse each section or search across the entire site using keywords or phrases. Each resource is identified with an icon, making it easier to see at a glance the different types of information, e.g. leaflets, support groups, etc. The results of a search are grouped with information leaflet titles first, followed by patient support groups, PatientPlus records, then directory pages and finally suggested books. The PatientPlus

articles add more depth on selected topics and are likely to be of particular interest to health professionals. They are written by an expert authoring team using sources such as randomised controlled trials, meta-analyses and guidelines. References are given for each leaflet, many of which are linked online directly to the full text source of the article or guideline.

NHS Direct: www.nhsdirect.nhs.uk

NHS Direct operates call centres, digital TV and a website, 24 hours a day, providing information and advice about health, illness and health services. There are several ways to find information on the NHS Direct website. A health encyclopaedia gives information and advice on a range of conditions, surgical procedures, medications, and health issues. This is searchable by subject or by body key. The body key allows you to click on a part of the body which brings up a list of the encyclopaedia articles concerned with that area. Some of the most popular health encyclopaedia topics have been translated into other languages. You can access these topics by clicking on the image in the bottom left-hand corner of every page on the website.

Other information includes answers to common health questions, based on the enquiries received most frequently by NHS Direct, such as 'What's a safe level of drinking?'. There is also a self-help guide that takes you through a series of questions about your symptoms and advises on what action to take – whether symptoms can be managed at home, if you need advice from an NHS Direct nurse, or whether you need to call for an ambulance. There is information about local health services and you can take part in some interactive quizzes. If you cannot find the information you need on the website you can send an enquiry to their information team who will provide information about named health conditions, treatments and NHS services. There is also a search facility allowing you to search across the website.

DIPEX: www.dipex.org

DIPEX offers a different approach to patient information by providing interviews with people describing their personal experiences of health and illness that you can watch, listen to or read. This provides patients with the opportunity of sharing an experience with someone in a similar position. It covers a range of conditions including cancers and screening, chronic

health issues, women's health, young people's experiences, and living with dying to name a few. The personal interviews are broken down into two sections: 'Talking about' and 'Individuals'. 'Talking about' allows you to find personal experiences by topic; for example, under breast screening there are areas on 'Going for a mammogram', 'Getting the results' and 'Views on breast screening'. Alternatively, choosing 'Individuals' allows you to search for interviews by age group.

Under the resources button for each topic is a list of organisations, support groups, academic papers and publications. Where possible each resource has been rated and evaluated using the DISCERN criteria, which are discussed in more detail below. A news section provides details of current press releases, and a forum provides an area for people to discuss health issues, although you will need to register to use it. The video and audio interviews use Windows Media Player (version 9) but there is a link to download this software under 'Help' if required.

Patient Information Gateway: [www.bsuh.nhs.uk/library/ PatientInformation/tabid/74/ Default.aspx](http://www.bsuh.nhs.uk/library/PatientInformation/tabid/74/Default.aspx)

Many NHS library services provide their own lists of patient information gateways. An example is the above website, created by the authors of this article, which includes links to the resources mentioned here plus many more specific sites. (Further topic-specific patient information sites can also be found in the Knowledgeshare article from March 2002.⁶)

Also included on this site is a database of patient information leaflets about medical conditions and hospital procedures that have been written specifically for patients and carers and is currently in use by healthcare staff at Brighton and Sussex University Hospitals NHS Trust. The database is continually growing as leaflets are developed and added to it. You can search this collection for a specific word or phrase or view all the leaflets together.

Cancerbackup: www.cancerbackup.org.uk

Most common conditions will have sites dedicated to providing topic-specific patient information. Cancerbackup is Europe's leading cancer information charity, with over 4500 pages of up-to-date cancer

information, practical advice and support for cancer patients, their families and carers. Their cancer information service has a freephone helpline or enquiries can be emailed to a cancer specialist nurse. The website is divided into sections on types of cancer, treatments, current trials, and resources and support. Information on specific cancers is then broken down further into topics such as causes, diagnosis and treatment.

Also listed are local support groups searchable by area, national support groups and Cancerbackup resources, booklets and related websites. The site can be searched using keywords or phrases and all information on the site is given a review date so it is clear when it was last updated. Finally, there is an area for health professionals where you can sign up for their e-newsletter, find out about cancer topics in the news and the academic press, search for treatment guidelines and look at a website of the month reviewed by Cancerbackup.

Royal Colleges

Many of the Royal Colleges include patient information on their websites. Two examples of this are The Royal College of General Practitioners (www.rcgp.org.uk/patients/patient_centre_home.aspx) and The Royal College of Surgeons of England (www.rcseng.ac.uk/patient_information). The former contains a very comprehensive collection of patient guides and web links, self-help guides, advice on choosing treatments and a section explaining GP services in general. The latter includes frequently asked questions on topics such as operations and types of surgery, information guides produced by the college which are free to download, information on their Patient Liaison Group and its newsletter, and links to a wide range of further information sources and public events such as lectures.

Lab Tests Online: www.labtestsonline.org.uk

One rather unique patient information site is Lab Tests Online, a peer-reviewed online resource that explains common diagnostic tests in a way that is clear and understandable for the lay person. The site is the result of collaboration between professional organisations representing the clinical laboratory community, and is partially funded by the Department of Health. Patients can choose a particular lab test from

the drop-down list to see details about when the test is likely to be requested, how the sample will be taken, and brief information about what the result might mean. These sections also include extra information on what may be associated with a particular abnormal result, e.g. pregnancy, physical activity, time of day, and so on.

It is also possible to search for, or select, a specific condition in order to find out more about it. There is quite a lot of detail about causation, symptoms and treatment of the conditions, as well as an overview of the various lab tests that may be used for diagnosis. As well as browsing by test or by condition, the user can select a specific age group in order to be presented with information on relevant screening tests.

As well as this condition-specific or test-specific information, Lab Tests Online also includes sections on understanding laboratory testing in general. 'Understanding your test' covers explanations of reference ranges, test reliability, coping with test-related pain and anxiety, and more. Finally, there is an area of the site that looks at the way laboratories work, how they are accredited and the various processes that a sample goes through.

Patients Association: www.patients-association.org.uk

The Patients Association is a registered charity offering independent information and advice, and providing patients with an opportunity to raise concerns and share experiences of health care. There is a helpline for people wishing to discuss their experiences of using health services or needing information on making complaints. Through the helpline, written correspondence and research the association learns from patients the issues that are of concern and works towards improving health care.

Campaign work is focused on the following areas: care of older patients; clean health service environments and control of infections; dentistry; primary care services; and trust in medicines. There are many books and reports published by the association free to download from the website, for example: *You and your dentist*. There is a 'News' section containing the latest features from the association and invited writers, and you can sign up to receive free updates, press releases and newsletters by email. A list of frequently asked questions under the 'Help and advice' section gives answers to queries such as how to access your medical record.

PALS Online: www.pals.nhs.uk

PALS Online is the website of the national network of NHS Patient Advice and Liaison Services. PALS were introduced across England in 2002; they provide information to patients and the public on the NHS, help to resolve any problems, concerns or complaints, give information on support groups and agencies, and ensure service managers are aware of issues being raised. The website provides the facility to search for PALS offices by area. It also links to other health and agency websites, provides resources for PALS workers to share with each other and the public, and reports the latest news about PALS service development.

Expert Patients Programme: www.expertpatients.nhs.uk

Self-management of long-term conditions is not just beneficial to the health economy but can improve the health of the patients themselves, often leading to a reduction in symptoms, significant decreases in pain and improved quality of life.⁷ The Expert Patient Programme has been set up to educate patients about their condition and develop their confidence in taking control over their illness. The programme consists of a series of evidence-based training courses that are currently being run by primary care trusts around the UK, and the site contains several case studies from patients who have attended the sessions, as well as from health professionals involved in the programme. You can find courses running in your area, with contact details to allow you to sign up, or find out how to train as a course tutor. There is an additional course for parents of children with long-term conditions, as well as a course for carers.

The site also provides a collection of resources on self-management of medical conditions, including a regular newsletter aimed at health professionals involved in this area. There are a number of reports evaluating various aspects of the Expert Patient Programme and a guide to setting up your own lay-led programmes (under the heading 'Stepping stones to success'). Finally, the links section contains an extremely useful list of self-help groups and national charities providing patient information and supporting patient involvement.

Contact a Family: www.cafamily.org.uk

Contact a Family is a UK-wide charity providing support, advice and information for families with disabled children. They provide a freephone helpline, put people in touch with others with similar experiences and campaign for better services for disabled children throughout the UK. A popular part of their website is the medical directory which provides information on specific conditions and over 900 rare disorders. Details of support groups and their publications are listed with each condition.

Another section of the website is devoted to rare disorders, describing what they are and giving links to further information, e.g. the Online Mendelian Inheritance in Man. There is also an area aimed at professionals and the website includes factsheets and research carried out by Contact a Family.

Discern: www.discern.org.uk

With the proliferation of websites offering information on illnesses and treatments, it can be difficult for patients and healthcare professionals to know which sites are accurate and evidence based. Discern is a tool that enables users to judge the reliability of a piece of patient information by answering a series of simple questions about the source. As well as being useful for individual patients, this questionnaire also allows healthcare staff to screen the information that they provide and can guide you in the production of your own educational literature.

The Discern instrument was developed according to a rigorous process, and details of this can be found on the site. The questions in the checklist focus on clarity, relevance and balance, and look at whether treatment options are described in sufficient detail, including information about side-effects and alternative courses of action.

Judge: web sites for health: www.judgehealth.org.uk

Another source for advice on the quality of online patient information is the Judge project which has

produced two sets of guidelines. One is aimed at helping consumers to make informed choices about websites and the other to assist support groups in producing clear, accessible and useful information. The site is run by a group of information managers from universities and charitable organisations. Judge is recommended by Patient UK and other well-known health information websites.

There are other websites offering useful guidance on this subject. An internationally recognised scheme is the HON Code of Conduct (www.hon.ch/HONcode/Conduct.html) from the Health on the Net Foundation, which offers support and accreditation to patient information websites. The site allows you to search for accredited sites. In a similar vein, the Department of Health has produced its own guide to writing patient information, which can be found at www.nhsidentity.nhs.uk/patientinformationtoolkit/patientinfotookit.pdf. This guide has been adapted for use by local NHS trusts and you should always check that any leaflets or websites that you create comply with local policy.

Conclusion

Patient information has a key part to play in the move towards increased patient choice. The idea of an information prescription, as well as initiatives like the Expert Patient Programme, empower patients to better understand and manage their conditions. Most recently, in April 2007, the Department of Health announced the development of a new Patient Choices website.⁸ Bringing together information on conditions, procedures, health promotion and directories of local hospitals with details of which are meeting their targets, this site will be backed up by trained public librarians who will offer support to patients in finding information and booking hospital appointments for themselves online.

In a recent study, 77% of patients said that 'easy, well-presented patient literature' would increase their confidence in a healthcare service.² Clearly it is important for staff to know where to find quality information and what rules to follow when developing leaflets or websites of their own. A recent *BMJ* editorial urges primary care organisations to ensure that the gaps in information provision are filled, as those who are missing out are the patients who 'most need good information and know least about health, thus accentuating inequalities in their health status'.⁵

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REFERENCES

- 1 Government News Network. *Tomorrow's Patients will have Information Prescribed alongside Medicines*. London: Department of Health, 2004. www.gnn.gov.uk/environment/fullDetail.asp?ReleaseID=235190&NewsAreaID=2&NavigatedFromDepartment=False (accessed 3 May 2007).
- 2 Hartigan N. What patients want from information leaflets. *British Journal of Healthcare Computing and Information Management* 2004;21:35–6.
- 3 McDonald VM and Gibson PG. Asthma self-management education. *Chronic Respiratory Disease* 2006;3:29–37.
- 4 Department of Health. *Better Information, Better Choices, Better Health: putting information at the centre of health*. London: Department of Health, 2004. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4098599.pdf (accessed 3 May 2007).
- 5 McCarthy K and Prentice P. Commissioning health education in primary care. *BMJ* 2006;333:667–8.
- 6 Beard R, Lehmann J and Springham S. Web alert: finding patient-focused information on the internet. *Journal of Clinical Governance* 2002;10:31–5.
- 7 Expert Patients' Task Force. *The Expert Patient: a new approach to chronic disease management for the 21st Century*. London: Department of Health, 2001. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018578.pdf (accessed 3 May 2007).
- 8 Government News Network. *Hewitt Unveils Patient Choice for All*. London: Department of Health, 2007. www.gnn.gov.uk/environment/fullDetail.asp?ReleaseID=277419&NewsAreaID=2&NavigatedFromDepartment=True (accessed 3 May 2007).

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