What information do patients need about medicines?

David Dickinson, D K Theo Raynor; James G Kennedy; Silvia Bonaccorso, Jeffrey L Sturchio

Partnership between health professionals and patients depends, in part, on the provision and exchange of accurate and reliable information about drugs, but who should provide it? We invited contributors to answer the question from the perspectives of patients, clinicians, and the pharmaceutical industry

Ask the patients—they may want to know more than you think

David Dickinson, D K Theo Raynor

People's appetite for information about their treatment is often greater than doctors believe.[1] Clearly, patients vary in the extent of their desire for partnership in making medical decisions. It follows that part of the duty of a health professional is to work out how much partnership a patient wants, and what information he or she needs to support that level of partnership.[2,3]

What do people want to know?

People have a broad range of information preferences that may differ at different times and for different reasons. They may want more information than prescribers want to give—for example, about the possible side effects of a drug.[1,4] They may place different interpretations on information about likely risks, and they may question the benefits of taking a drug when they are not greatly concerned by the medical "problem" that the treatment is meant to solve. They may well rate the practicalities of how to take a drug higher than the details of the inert components of the pills or the drug manufacturer's address.

In interviewing people about drug treatments,[5,6] we have consistently noticed that people respond to four essential aspects of a drug:

- Side effects
- What it does and what it's for
- Do's and don'ts
- How to take it.

Who is trusted as a source of information?

Our work with medicine users shows clear trends, in common with consumer surveys:

- Health professionals are the most popular source for drug advice
- Electronic media (internet and television) are becoming important sources
- Non-expert help (such as friends and family) is always popular.

A range of information sources is preferred, but that doesn't challenge health professionals' premier position. Lay or non-expert sources are generally used to help people fit expert information into their everyday life or to fill the gaps after a consultation that left certain questions unanswered.

It follows that the ideal source of drug information would be

- Accurate, up to date, reliable, and practically useful
- Accessible in language, format, and tone
- Capable of customisation or personalisation
- Available at different levels of detail at different times
- Informative about conditions as well as treatments
- Striking a balance between a treatment's beneficial and adverse effects
- Available at the time of a consultation and consistent with best advice
- Linked to other reliable and consistent sources of advice and information.

A structured source of information to enable better use of drugs in Britain is being piloted as part of "Ask about medicines week." Under the guidance of an advisory board that includes representatives of patients, health professionals, regulatory authorities, and the drug industry, new sources of information have been drafted. Medicine guides—practical online guides to individual drugs—are linked to new content on NHS Direct Online about the conditions being treated. The pilot project covers epilepsy and colds and flu. The aim of the project is to provide access to consistent, high quality, multilevel patient information that complements the detailed information leaflets contained in most drug packs. This information should eventually be accessible in multiple media and could be used by doctors, nurses, and pharmacists for personalised counselling whenever drugs are prescribed or dispensed.

Contributors and sources: DD is a health communications specialist and former editor of *Health Which?* magazine. He is currently co-chair of Ask About Medicines Week, an initiative to change the way people talk about drug treatments. DKTR is an academic pharmacist with a special interest in communication, and this article draws on his 20 years of research into people's needs for drug information.

Competing interests: DD has been paid by several pharmaceutical companies to conduct user testing of patient information leaflets.

1 Berry DC, Michas IC, Gillie T, Forster M. What do patients want to know about their medicines, and what do doctors want to tell them? A comparative study. *Psychol Health* 1997;12:467-80.
2 Blenkinsopp A, Bashford J, Dickinson D. Health professionals need to identify how much information patients want. *BMJ* 1998;317:413.
3 Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999;318:318-22.
4 Berry DC, Knapp P, Raynor DK. Provision of information about drug side effects to patients. *Lancet* 2002;359:853-4.
5 Dickinson D, Raynor DK, Duman M. Patient information leaflets for medicines: using consumer testing to determine the best design. *Patient Educ Couns* 2001;43:147-59.
6 Raynor DK, Savage I, Knapp P, Henley J. We are the experts: people with asthma talk about their medicine information needs. *Patient Educ Couns* (in press).

Consumation,
53 Hosack Road,
London
SW17 7QW
David Dickinson
consultant in consumer information design

Pharmacy Practice and Medicines Management Group, University of Leeds, Leeds LS2 9JT
D K Theo Raynor
professor of pharmacy practice, medicines and their users

Correspondence to:
D Dickinson
david.dickinson@consumation.com

BMJ 2003;327:861–4

"Doc, tell me what I need to know"—a doctor's perspective

James G Kennedy

Cedar Brook
Practice,
11 Kingshill Close,
Middlesex
UB4 8DD
James G Kennedy
general practitioner
jim@the-core-resource.com

The most common medical intervention is the prescribing of drugs. In Britain over 80% of the population receives at least one prescription over a five year period.[1] Increased patient involvement in health care, a result of sociopolitical changes,[2] improves health outcomes.[3] Informed decision making by patients and doctors working in partnership towards concordance about treatment requires the ready availability of reliable and understandable information. What should be the sources and formats of this information?

Currently, information on contraindications, side effects, interactions, and dose is provided on patient information inserts within drug packets required by licensing authorities. This is usually produced in minute typeface, is legalistic in wording, and is defensive in tone. Unsurprisingly, patients and doctors often find such information discouraging and unhelpful in determining the balance between risk and benefit.

Drug prescribers and dispensers make variable efforts to discuss drugs with patients. Further information is sometimes available from charities, patient support groups, or the internet. There is little published evidence on patients' actual information requirements, no systematic quality control or tailoring of information for individual patients, and little training for doctors or patients in the necessary communication skills.[4]

Information providers should be aware of ethnic, cultural, sex, and age differences in the information needs of patients, and in their culturally determined interpretation of data. However, it would be wrong to generalise about, or assume, the degree of involvement a particular patient will prefer in treatment decisions. Patients' preferences should be explored when the prescription is introduced, and checked again in subsequent consultations.[4]

The communication of risk in numerical terms is by no means always appropriate or meaningful for patients. Metaphors and examples (such as "It is safer to take this course of drugs than to drive home from the surgery") may be more appropriate.[5] Some patients may not want to be given such information and, providing they will not be harmed by that choice, we should respect their wishes. The information we do provide ought not to be limited to the drug prescribed, but should embrace alternative prescriptions and other modes of treatment.

The amount and complexity of information must be tailored to the perceived needs of a patient. Access to further information should be facilitated, and patients helped in interpreting the data. The internet has greatly expanded the availability of information, but this is often disjointed, incomplete, apparently conflicting, and not aimed at a general audience. The use of information from the web varies considerably across socioeconomic groups. Therefore, to improve access to information, it should in future be provided in a variety of formats—spoken, written, and pictorial. Such information will need to be available as an adjunct to consultations—by telephone, fax, email, text messaging, and post, as well as on the web. The advent of digital radio and television makes likely the development of a raft of specialised medical broadcast channels.

"Take one of these tablets tonight, Mr Tate, and one more if you wake up tomorrow morning"

Prescribing clinicians have a key role in ensuring patients have adequate access to information and helping them to interpret this information. Health services are responsible for ensuring the information exists and is reliable and accessible. Pharmaceutical companies have the greatest repository of data on their drugs, but their impartiality may be questioned. Special interest groups (charities, pressure groups) may have their own drums to beat.

I would like to see the establishment of a specialised and rigorous "information source" independent of both the health service and pharmaceutical industry. It would act as an quality controller for information from a variety of sources—research communities in universities, specialist professional bodies, and pharmaceutical companies. Such a trusted resource could monitor, assess, and interpret the research evidence in each clinical area and become an authoritative, but not exclusive, information provider for clinicians and the public. It could also be invited to develop and test methods for information dissemination.

Clinicians, particularly general practitioners (who often can build on long term relationships with patients), must take a lead in information sharing with patients. There will be understandable concerns about the need for yet more time for yet more clinical tasks. It seems logical, however, to argue that early engagement of patients in decision making about treatment should prevent much subsequent morbidity and confusion and may, even in the short to medium term, save time as well as improve outcomes.

Contributors and sources: JK is a general practitioner, with research interests in primary care prescribing and use of drugs. He is prescribing spokesman for the Royal College of General Practitioners and has sat on NHS, UK Department of Health, and international prescribing working groups.

Competing interests: None declared.

1 National Audit Office. *Repeat prescribing by general medical practitioners in England.* London: HMSO, 1993.
2 Department of Health. *The expert patient: a new approach to chronic disease management for the 21st century.* London: DoH, 2001:12.
3 Greenfield S, Kaplan S, Ware JE. Expanding patient involvement in care. *Ann Intern Med* 1985;102:520-8.
4 Say RE, Thomson R. The importance of patient preferences in treatment decisions—challenges for doctors. *BMJ* 2003;327:542-5.
5 Edwards A, Elwyn G, Mulley A. Explaining risks: turning numerical data into meaningful pictures. *BMJ* 2002;324:827-30.

Perspectives from the pharmaceutical industry

Silvia Bonaccorso, Jeffrey L Sturchio

Merck & Co, One Merck Drive, Whitehouse Station, NJ 08889-0100 USA
Silvia Bonaccorso *vice president, Marketing and Medical Services*
Jeffrey L Sturchio *vice president, External Affairs, Europe, Middle East and Africa*

Correspondence to: S Bonaccorso silvia_bonaccorso@merck.com

"Drugs don't work in patients who don't take them." This famous observation by C Everett Koop, former US surgeon general, is reinforced by the findings of a recent World Health Organization report on adherence to long term treatments. On average, half of the patients prescribed drugs for chronic conditions (such as hypertension, hypercholesterolaemia, and diabetes) in developed countries stop taking them after a year, and adherence rates are even worse in developing countries. The WHO concludes that improving adherence requires multidisciplinary and multilevel interventions that take individual patients' experiences of illness seriously. The impact of non-compliance—through avoidable morbidity and mortality, the cost of additional medical interventions, and (indirectly) lost productivity at work—adds considerably to the costs of health care.[1]

Providing access to accurate, balanced, evidence based, and comprehensive information about healthcare options is particularly important in improving patients' adherence to treatment. When they are prescribed drugs, patients should also be able to obtain easily understandable information about the expected benefits and potential outcomes, and any risks, interactions, and side effects.

Condition Guides can help you learn about and manage specific medical and health conditions with credible information resources, patient education, and interactive tools.

Women, Men, Children, and Seniors have unique health needs. Find information on fitness, nutrition, prevention, and how you and your loved ones can maintain a healthy lifestyle.

- Now in Spanish! A.D.A.M. Encyclopedia
- Check out the Condition Briefs or comprehensive Condition Guides
- Check out the NEW Interactive Human Atlas!

Enter here to find a variety of care and support resources that can help you take a more active role in your health.

A Harvard Health E-Newsletter from Harvard Medical School

Register now on MerckSource to receive a complimentary subscription to the Harvard Health E-Newsletter. This monthly publication features selections from Harvard Medical School's monthly newsletters addressing men's health, women's health, general health, and news.

MerckSource provides patients and caregivers in the United States with a comprehensive guide to online health information and related resources they can use when they need them

How can the pharmaceutical industry help?

European patients and consumers are increasingly demanding better access to such information to help them make informed choices about their health.[2] Patients who take an active role in managing their health have better health outcomes than those who do not, and are therefore cost effective patients for society. This reinforces the case for better information for patients: it makes sense for both patients and the healthcare system.[3]

Pharmaceutical companies—which often have the best information on the drugs they discover, develop, manufacture, and market (with each activity carefully regulated at both European and national level)—have a role to play in meeting this demand for accurate and reliable health information. Such companies are uniquely positioned to provide comprehensive scientific and clinical information, where allowed by law, about their products based on the data obtained through the arduous process of preclinical research and clinical and regulatory development. These resources will be particularly important as doctors help patients to understand the optimum use of drugs, how to manage any side effects, and how to maximise their benefits by adherence to the proper regimen.

Evidence from consumer surveys and other studies show, for example, that "direct to consumer" communications from pharmaceutical companies provide valuable information on the benefits of treatments (and on risks and side effects); motivate consumers to seek additional information from physicians, pharmacists, and other sources; and help patients to improve adherence to treatment and make behavioural changes to improve health.[4 5]

Looking ahead

We think that patients and consumers would benefit most from a variety of tools to help them navigate through the wealth of information available from print, broadcast, and electronic sources, coupled with clear guidelines for judging the quality of the information (such as those proposed for internet information sources by the European Federation of Pharmaceutical Industries and Associations[6]), along with training in health literacy for consumers and providers. Developing such initiatives—and deciding how they should be structured, funded, and maintained—is an important opportunity for the European public health agenda in the years ahead.

What might such information sources look like in practice? Merck's website (www.merck.com) provides an example of what a pharmaceutical company can offer, in its section Patients and Caregivers and in the *Merck Manual Home Edition*. The latter provides complete information about many therapeutic areas written in readily understandable language. The MerckSource website offers a portal into an extensive library of authoritative and readable reference works, balanced information on medical conditions and general health issues, and practical guides (from an independent source) of questions for patients to ask their physician (see figure). Unlike advertising, which is broadcast or "pushed" at people, these information resources are available to be "pulled" from the web when consumers and patients choose to seek them out.

Conclusions

Liberalisation of the guidelines governing direct to patient information from the pharmaceutical industry (in both print and electronic form) would help to broaden the range of resources available to patients who want to take a more active role in their own health care, enrich the dialogue between patients and health professionals, and thus improve adherence to long term treatment, with consequent improvement in clinical outcomes.

Contributors and sources: SB is responsible for (among other areas) global patient information materials related to Merck products and for much of the content of www.merck.com. JLS has worked with US and European patient organisations on health policy issues (including information for patients) for the past decade. He is a former member of the editorial advisory board of the *Patients' Network*.

Competing interests: Both authors are full time employees of Merck & Co, also known as Merck Sharp & Dohme.

1 World Health Organization. *Adherence to long-term therapies: evidence for action.* Geneva: WHO, 2003.
2 Coulter A, Magee H, eds. *The European patient of the future.* Maidenhead: Open University Press, 2003.
3 Greenfield S, Kaplan SH, Ware JE. Expanding patient involvement in care: effects on patient outcomes. *Ann Intern Med* 1985;102:520-8.
4 Bonaccorso SN, Sturchio JL. For and against: Direct to consumer advertising is medicalising normal human experience: against. *BMJ* 2002;324:910-1.
5 Calfee JE, Winston C, Stempski R. Direct-to-consumer advertising and the demand for cholesterol-reducing drugs. *J Law Economics* 2002;45:673-90.
6 European Federation of Pharmaceutical Industries and Associations. *Guidelines for internet web sites available to health professionals, patients and the public in the EU.* Brussels: EFPIA, 2001. (www.efpia.org/6_publ/Internetguidelines.pdf)

"Doing prescribing": how doctors can be more effective

Glyn Elwyn, Adrian Edwards, Nicky Britten

What is the best way to achieve concordance? The authors summarise the evidence and indicate the way ahead for doctors to involve patients in making decisions about treatment

Primary Care Group, Swansea Clinical School, University of Wales Swansea, Swansea SA2 8PP
Glyn Elwyn *professor*
Adrian Edwards *reader*

Institute of Clinical Education, The Peninsula Medical School, Exeter EX1 2LU
Nicky Britten *professor of applied health care research*

Correspondence to: G Elwyn g.elwyn@swansea.ac.uk

BMJ 2003;327:864–7

Much prescribed medicine is not taken, and we know that few patients adhere to "prescription" guidance.[1] It is also clear that patients' beliefs and attitudes influence how they take drugs.[2] This is particularly true for preventive medicine (thus largely for conditions without symptoms) and for drugs that have side effects or other drawbacks. As interest in the concept of patient autonomy increases, we are becoming more aware, and more respectful, of intentional dissent—where better informed patients decline certain drugs.[3] Concordance describes the process whereby the patient and doctor reach an agreement on how a drug will be used, if at all. In this process doctors identify and understand patients' views and explain the importance of treatment, while patients gain an understanding of the consequences of keeping (or not keeping) to treatment.

Evidence base

Few well conducted, randomised controlled trials of interventions to help patients follow their prescriptions have been done.[4] Our article is based on a number of reviews in this field and a recent systematic review of concordance.[1 4–6] Changes in terminology in

"When we want your opinion, we'll give it to you"

PUNCH CARTOON LIBRARY