White Rose Research Online

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk
Universities of Leeds, Sheffield and York

Deposited via The University of Leeds.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/id/eprint/4909/

Article:
Dickinson, D. and Raynor, D.K.T. (2003) Ask the patients - they may want to know more than you think. BMJ, 327 (7419). p. 861. ISSN: 0959-8138

https://doi.org/10.1136/bmj.327.7419.861-a

Reuse
See Attached

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

UNIVERSITY OF LEEDS
University of Sheffield
UNIVERSITY of York

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