

EDITORIAL

Meeting the information needs of patients with allergic disorders: partnership is the key

H. Pinnock and A. Sheikh

Introduction

The Department of Health's recently launched Expert Patient Initiative seeks, through empowering patients to be partners with health-care professionals in decisions made about their health care, to achieve sustainable improvements in quality of life for people with chronic disorders [1]. Access to appropriate, accurate, unbiased and comprehensible information is a cornerstone of this policy and, moreover, a fundamental right for all patients, not only to enhance understanding, but also to inform choice of treatment and facilitate self-management. This may be particularly important in the context of allergic conditions given the burden of disease [2], acknowledged deficiencies in primary-care management [3], and very limited availability of specialist services in the UK [4]. The observational study by White et al. [5] in this month's journal suggests that the currently available patient information leaflets for hayfever may not be helping to achieve these objectives [5].

The need for unbiased information

Written information has an important role in supplementing the advice provided in consultations and may usefully reinforce self-management training [6, 7]. Within the context of consultations, clinicians have a personal responsibility to read the leaflets handed out to patients to check that their contents accurately reflect the advice being issued and are furthermore appropriate to the needs of the patient.

However, only about half of sufferers with hayfever actually seek professional advice from their general practitioners (GPs), many preferring to self-treat [8, 9]. This preference for the convenience of over-the-counter medications presents specific challenges for the provision of high-quality information. It is understandable that the commercial pressures of selling on supermarket shelves will influence the content of leaflets produced by pharmaceutical companies, but the extent of the bias detected by White and his colleagues in leaflets from general practices and pharmacies is of concern. The major inaccuracies detected in the leaflets reflected a failure to describe a full range of treatment options and provoked comments from the researchers ranging from, 'economical with the truth' to 'obvious advertising'.

Government policy is to widen access to over-the-counter medication with the stated aim of, 'extending patient choice' and giving patients 'greater control of their treatment' [10]. By coincidence, the first prescription-only medicine to be

'fast-tracked' and made available over-the-counter under the 2002 regulations was Flixonase Allergy, but many more preparations will follow. The aim of empowering patients will only be realized if patients have access to accurate, unbiased information that enables them to make informed choices. The broader challenge for health professionals is to accept that they have a responsibility not only for the information they give their patients personally, but also for the 'over-the-counter' leaflets and e-health advice available to sufferers who choose not to consult.

Ensuring the quality of information

Clinical accuracy and unbiased content are fundamental. It may therefore be practical to link the production of patient information to the publication of evidence-based guidelines and/or systematic reviews. There are already precedents for this: for example, the National Institute for Clinical Excellence include 'Information for the Public' with their publications [11]. Similarly, *Best Treatments* is a lay publication which complements the evidence-based reviews in *Clinical Evidence* [12]. Organizations such as the British Society of Allergy and Clinical Immunology, who are involved with guideline development [13], could consider adopting this practice.

It is important to draw on patient advice, not only about the design and readability of patient information leaflets but also to help define the content [14]. Since 1995, *American Family Physician* has published an extensive series of information sheets for patients drafted by the authors of reviews, but comprehensively edited and field tested by lay readers [15].

Ensuring accessibility for different population groups

Clearly it is important that leaflets generally available from surgeries and pharmacies are written with clarity and use language understood by most readers. 'Translating' clinical evidence into plain English is fundamental and alternative formats such as Braille or audiotapes should be considered for those with visual impairment. Translating leaflets into other languages, however, requires more than just converting text, as cultural differences need to be considered [16]. However, ensuring a primary school reading age does little to meet the needs of university graduates who may find such leaflets superficial and/or patronizing. Websites are

particularly well suited to providing different layers of information. NHS Direct provides very simple advice, but has a link to *Best Treatments*, which has a section on hayfever [<http://www.besttreatments.co.uk/btuk/conditions/16486.html>] that allows readers to explore the subject to their chosen depth.

The need for a multi-faceted dissemination strategy

Thought needs to be given to facilitating dissemination within pharmacies, GP surgeries and hospitals. Having a stock of patient information leaflets is not enough. Patients may be reluctant or too embarrassed to pick up leaflets from displays in public areas if they feel they may be observed. Both community pharmacies and general practices deal with such a wide range of conditions that there are practical difficulties in ensuring easy availability of leaflets for even the more common conditions. Being able to locate a leaflet when asked to do so for a survey is not the same as having the information to hand when it is required for a patient in the course of a brief consultation. Electronic links to leaflets that can be printed by the pharmacist and GP computers may be more convenient than searching for paper leaflets in a filing cabinet. Prodigy (electronic guidelines linked to primary-care computer systems in England and Wales) has a wide range of leaflets available [<http://www.prodigy.nhs.uk/guidance.asp?gt=allergic+rhinitis>]. Brief advice and sources of further information could be printed on the tear-off slip of a computerized prescription. Linking the provision of information in this way to prescriptions or consultations, and ensuring that it is available when the patient has a concern they wish to investigate is likely to ensure the maximum benefit [17].

The potential benefits of providing information

There is much to be gained by encouraging the development, accessibility and ultimately use of high-quality patient information. Leaflets not only satisfy patient's need for information [18], but effectively support the clinician's advice [19, 20], and may reduce re-consultations [21]. Sufficient knowledge is a prerequisite of concordance [22], and written information underpins the success of self-management plans now available for a range of chronic conditions, most notably asthma [7].

An unexpected benefit may be the improvement of clinical standards. When patient information leaflets were first required to be inserted in the packaging for all dispensed drugs it was argued that providing such detailed information would place new demands on the knowledge of prescribers [23]. It is important to note in this respect that the Pharmaceutical Society of Great Britain is currently addressing the increased information needs of pharmacists involved in counselling patients on the use of newly licensed over-the-counter drugs. Also relevant is that studies of asthma self-management suggest that patients with Asthma Action Plans may attract better treatment (i.e. increased inhaled steroid provision) from their attending clinicians [24, 25]. Providing

patients with the resources to influence the care they receive may be an effective strategy to disseminate specialist knowledge and improve the management of rhinitis in the community, fulfilling a key objective of the Expert Patient Initiative.

What is the way forward?

Five years ago, an editorial, commenting on a previous survey by Smith et al. [26] which highlighted deficiencies in the quality of leaflets for people with asthma, concluded that there was a need for a national public health information strategy which, 'recognises the advantages in raising standards and the risks of not doing so'. In a more recent debate on direct-to-consumer advertising of drugs, the Consumer's Association argued strongly in favour of one central, impartial source of information on treatments, independent of commercial bias [27]. Working in partnership with primary-care groups (such as the General Practice Airways Group), pharmacists and patient organizations, specialist organizations such as the British Society of Allergy & Clinical Immunology may consider offering to 'kite-mark' information leaflets and websites which meet standards of accuracy, impartiality and readability. Any kite-mark should, however, only be valid for a specified period of time as even the best leaflets will need regular updates in the same way as the best evidence-based guidelines now have predetermined review dates [28].

The growing expectation that patients will be expert partners in their health care, exercising choice and sharing the responsibility for decisions lends urgency to the call for a strategy to improve the quality and accessibility information available to patients. The British Society for Allergy & Clinical Immunology has an opportunity to lead the way in ensuring that this call is not left unheard.

Acknowledgements

We thank Dr Gill Hawksworth, consultant pharmacist, for her helpful comments on the manuscript.

References

- 1 Department of Health. The Expert Patient: A new approach to chronic disease management for the 21st century. London: Department of Health, 2001.
- 2 Gupta R, Sheikh A, Strachan DP, Anderson HR. Burden of allergic disease in the UK: secondary analyses of national databases. *Clin Exp Allergy* 2004; 34:520–6.
- 3 Levy ML, Price D, Zheng X, Simpson C, Hannaford P, Sheikh A. Inadequacies in UK primary care allergy services: national survey of current provisions and perceptions of need. *Clin Exp Allergy* 2004; 34:518–9.
- 4 Royal College of Physicians. Allergy: the unmet need: a blueprint for better patient care. Report of a working party. Royal College of Physicians, London, 2003.
- 5 White P, Smith H, Webley F, Frew A. A survey of the quality of information leaflets on hay fever available from general practices and community pharmacies. *Clin Exp Allergy* 2004; 34:1438–43.

- 6 Gani F, Pozzi E, Crivellaro M, Senna G, Landi M, Lombardi C et al. The role of the patient training in the management of seasonal rhinitis and asthma: clinical implications. *Allergy* 2001; 56:65–8.
- 7 Gibson PG, Powell H, Coughlan J et al. Self-management education and regular practitioner review for adults with asthma (Cochrane Review). In: *The Cochrane Library*, Issue 2, 2004. Chichester, UK: John Wiley & Sons, Ltd.
- 8 Richards S, Thornhill D, Roberts H, Harries U. How many people think they have hay fever and what they do about it. *Br J Gen Pract* 1992; 42:284–6.
- 9 Scadding GK, Richards DH, Price MJ. Patient and physician perspectives on the impact and management of perennial and seasonal allergic rhinitis. *Clin Otolaryngol Allied Sci* 2000; 25: 551–7.
- 10 Department of Health., Wider access to medicines to allow patients to manage their own healthcare. http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4013160&chk=3Npykd (accessed 14.5.2004).
- 11 National Institute for Clinical Excellence., *The Guideline Development Process – An Overview for Stakeholders, the Public and the NHS*. Issued: February 2004. <http://www.nice.org.uk/Docref.asp?d=106883> accessed 13.5.04.
- 12 Sheikh A, Panesar S, Dhami S. Seasonal allergic rhinitis. *Clini. Evidence* 2003; 9:585–97.
- 13 British Society for Allergy and Clinical Immunology. ENT Sub-committee Rhinitis Management Guidelines. London: Martin Dunitz Ltd, 2000.
- 14 Duman M, Farrell C. Practicalities of producing patient information (PoPPi) guide. London: King's Fund, 2000.
- 15 Wright J. AFP's patient information revisited. *Am Fam Physician* 2000; 62:709.
- 16 Griffiths C, Foster G, Barnes N et al. Specialist nurse intervention to reduce unscheduled asthma care in a deprived multiethnic area: the East London randomised control trial for high risk asthma. *BMJ* 2004; 328:144–7.
- 17 Fitzmaurice DA. Written information for treating minor illness. *BMJ* 2001; 322:1193–4.
- 18 Barlow JH, Wright CC. Knowledge in patients with rheumatoid arthritis: a longer term follow-up of a randomised controlled trial of patient education leaflets. *Br J Rheumatol* 1998; 37:373–6.
- 19 Macfarlane J, Holmes W, Gard P, Thornhill D, Macfarlane R, Hubbard R. Reducing antibiotic use for acute bronchitis in primary care: blinded, randomised controlled trial of patient information leaflet. *BMJ* 2002; 324:91–4.
- 20 Cates C. An evidence based approach to reducing antibiotic use in children with acute otitis media: controlled before and after study. *BMJ* 1999; 318:715–6.
- 21 Macfarlane JT, Holmes WF, Macfarlane RM. Reducing re-consultations for acute lower respiratory illness with an information leaflet: a randomised controlled study of patients in primary care. *Br J Gen Pract* 1997; 47:719–22.
- 22 Medicines Partnership., *What is concordance?* <http://www.medicines-partnership.org/about-us/concordance> (accessed 7.6.04)
- 23 Collier J. Patient information leaflets and prescriber competence. *Lancet* 1998; 352:1724.
- 24 Osman LM, Calder C, Godden DJ et al. A randomised controlled trial of self-management planning for adult patients admitted to hospital with acute asthma. *Thorax* 2002; 57:869–74.
- 25 Thoonen BPA, Schermer TRJ, van den Boom G et al. Self-management of asthma in general practice, asthma control and quality of life: a randomised controlled trial. *Thorax* 2003; 58:30–6.
- 26 Coulter A. Evidence based patient information. *BMJ* 1998; 317:225–6.
- 27 Garlick W. Should drug companies be allowed to talk directly to patients? *BMJ* 2003; 326:1302–3.
- 28 . Scottish Intercollegiate Guideline Network SIGN 50, a guideline developer's handbook. SIGN publication no 50. Edinburgh: SIGN, 2002.

H. Pinnock and A. Sheikh
Division of Community Health Sciences; GP Section
University of Edinburgh, 20
West Richmond St
Edinburgh, EH8 9DX, UK
E-mail: aziz.sheikh@ed.ac.uk