

A survey of the quality of information leaflets on hayfever available from general practices and community pharmacies

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Summary

Background Hayfever affects at least one in 10 people. The majority of hayfever is managed in the community setting where the management options are pharmaceutical and behavioural. Hayfever medications are available over the counter and on prescription from the general practitioner. Patient information leaflets are published to augment the advice given and to promote self-management, but these leaflets have rarely been subjected to critical review.

Objective To assess the quality of patient information leaflets written for people with hayfever and available from general practices and from community pharmacists.

Method A structured review of patient information leaflets about hayfever. During the peak grass pollen season copies of all leaflets available were collected from a random sample of community pharmacists and general practices in Wessex. The characteristics of the leaflet were recorded and the contents and presentation of each one was reviewed using the British Medical Association patient information appraisal system. Readability was assessed using the Simple Measure of Gobbledygook (SMOG). Two allergy-accredited specialists assessed each leaflet for accuracy.

Results During the peak pollen season no leaflets were available in 30% of the Community Pharmacists and 23% general practices. In total, 38 different leaflets were identified. All the leaflets reviewed were written for adults. Forty-seven percent of the leaflets had no publication date and one-third of those dated were at least 5 years old. In general the leaflets scored highly on issues of presentation, but less than half contained information on the full range of management and treatment options, many being biased towards a single or limited range of interventions. Seventy-nine percent leaflets were produced or sponsored by pharmaceutical companies and gave prominence to their own products. All the leaflets had readability scores requiring at least secondary education (SMOG score equal or greater than 9). At least one factual inaccuracy was identified in four-fifths of leaflets.

Conclusion A large number of leaflets are published for people with hayfever, but they are of variable quality and not accessible to all patients because of limited distribution or high readability scores. If all patients are to benefit from written information the authors and publishers of leaflets need to follow published recommendations, especially with respect to content and readability. In the absence of a national public health information strategy or a body that systematically vets patient information materials, clinicians must pay attention to the quality of information provided for or obtained elsewhere by their patients.

Keywords hayfever, patient information leaflets, quality, readability

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Introduction

It has long been recognized that good communication has a beneficial effect on clinical outcomes [1]. Recent years have seen a rapid growth in the availability of patient information materials, including leaflets, videos and material on the World Wide Web. Patient information leaflets are designed to

promote better health and prevent disease, to encourage self-care and reduce inappropriate service use, to ensure the appropriate treatment decisions and to improve the effectiveness of clinical care. Much well-intentioned effort goes into the development of such material but making the leaflets available is not enough: the information they contain must be accurate, relevant and comprehensive. Several studies have recently highlighted specific problems with literature relating to some chronic conditions [2–4] but this is the first critical review of patient information leaflets for people with hayfever.

Hayfever affects at least 10% of the general population [5]. The majority of hayfever is managed in the community

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setting by patients themselves with advice from their general practitioners or local pharmacist. The management options are behavioural and pharmaceutical. Since many hayfever medications are available over the counter as well as on prescription from the GP, we chose to focus our study on the leaflets available in community pharmacies and in GPs surgeries.

Method

In June 2000, 44 general practices from the Wessex Primary Care Research Network and 94 community pharmacists were invited to participate in this study. They were asked to identify within their practice all patient information leaflets pertaining to hayfever and return an example of each to the research team. A padded A4 envelope, together with stamps to cover postage up to 1000 g, was provided and any extra postage costs were reimbursed subsequently. Volunteers were also invited to participate in the reviewing of leaflets. The returned leaflets were coded and analysed as described below.

Analysis of materials

Characterization of materials

Each leaflet was catalogued by a single investigator (F. W) with respect to the source, date of publication, primary intended audience and size (booklet, leaflets or sheet).

Readability analysis

Two investigators assessed the readability of each leaflet using the Simple Measure of Gobbledegook (SMOG) formula [6]. A score of 3–8 equates with completion of primary education. Completed secondary education is needed for reading material of SMOG scores of 9–12 and tertiary education is required to comprehend SMOG scores of 13 and above.

This formula was used, as it is simple, widely used, repeatable and accurate in determining the reading level. To derive the score a total of 30 sentences are taken (10 from the start, 10 from the middle and 10 from the end of the leaflet) and the number of words containing three or more syllables are counted. The SMOG score is the square root of the total word count plus 3. When there was a discrepancy of more than 1 scale point both reviewers reassessed the leaflets. For eight leaflets containing more than 20 sentences but less than 30 sentences the polysyllabic word count was made and adjusted pro rata [7]. Two leaflets were too short to calculate a readability score.

Accuracy of the leaflets

Each leaflet was assessed independently by two accredited allergy specialists for two categories of inaccuracy: minor and major. Their judgements were based on evidence-based treatment guidelines [8] and clinical expertise. Minor inaccuracy was defined as one that would not seriously jeopardise the patient's understanding or self-care and a major inaccuracy as one that could lead to inappropriate self-medication or utilization of health services.

Presentation and content

Various checklists have been proposed to enhance the quality of health information [9–11]. We chose the British Medical Association (BMA) Patient Information Award appraisal form because it reviews both issues of presentation and content. It has 35 criteria covering accessibility, readability, comprehensibility, style and attractiveness of presentation, relevance and utility. The checklist has each criterion worded as a question, for example 'Is the target audience clearly stated?', 'Are quality of life issues addressed?', 'Does it include referenced statements?' Each criterion is judged yes, no, don't know or not applicable.

Nine practice nurses, five community pharmacists and two GPs agreed to participate in the review of leaflets. Three health professionals independently reviewed each leaflet and their results were collated. The majority decision about an individual criterion was taken when the judgements of the three observers were not congruent. The total score for each leaflet and the frequency with which individual criteria were met were calculated.

Results

Of the practitioners invited to participate in this study, 59% general practices (26/44) and 35% (33/94) community pharmacists agreed to participate. They returned a total of 82 leaflets, of which eight were not 'patient information leaflets pertaining to hayfever' and were excluded from further analysis. Three of the discarded leaflets were written for health professionals not patients, while five did not focus on hayfever but on the common cold (2), asthma (2) or an allergy charity (1) (Fig. 1). Ten (30%) community pharmacists and six (23%) general practices responded that they had no leaflets about hayfever available to their patients.

Characterization of materials

Among the 74 eligible leaflets returned, there were 38 different publications; 22 different publications were sent from general practices and 17 from community pharmacists, with only one leaflet being found in both settings. The leaflets were published by 24 different agencies, but over three-quarters (30/38; 79%) were linked to a commercial organization. Date

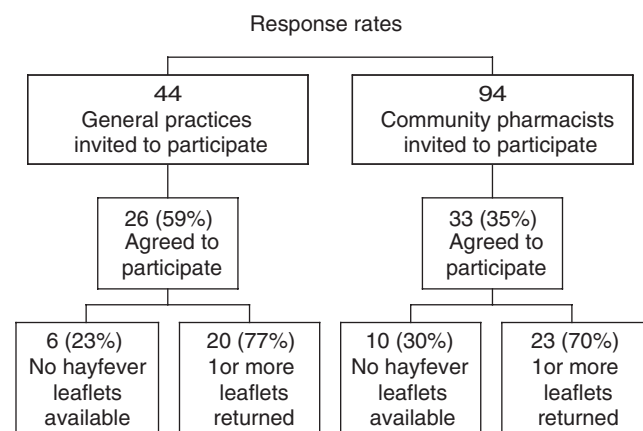


Fig. 1. Response rates.

Table 1. Characteristics of leaflets (*n* = 38)

Source	Number	Percentage
Drug companies or other commercial organizations	28	74
Charities	6	16
Charity/commercial collaboration	2	5
Other	2	5
Date of publication		
0–2 years before	7	18
3–5 years before	7	18
6 or more years	6	16
Not stated	18	47
Target audience		
Children or adolescents	0	0
Adults	38	100
Size		
A5 booklets (eight pages and more)	11	29
Pocket-sized booklet	4	11
A4 sheet	5	13
Leaflet (folded A4)	10	26
Small sheet	8	21

Table 2. Readability of patient information leaflets about hayfever (*n* = 36)

Simple Measure of Gobbledegook grade	No. (%) of leaflets	Cumulative (%)
9	4 (11)	11
10	5 (14)	25
11	13 (36)	61
12	8 (22)	83
13	4 (11)	94
14	2 (6)	100

of publication was not apparent in almost half of the leaflets. In 30% of the leaflets where it was stated, it was in excess of 5 years previous. All leaflets were targeted at an adult audience and their formats were varied, from single A5 sheets to booklets of 20 pages or more (Table 1).

Readability analysis

The reading grade for these publications ranged from 9 to 14 (mode 11, mean 11.2, SD 1.3) (Table 2). Two of the leaflets reviewed had been awarded a Crystal Mark by the Plain English Campaign. These both had a SMOG score of 9.

Accuracy of leaflets

A total of 36 minor and 11 major inaccuracies were identified. Eight leaflets (21%) were judged to be completely accurate, 19 (50%) had minor inaccuracies and 11 (29%) contained a major inaccuracy. The concordance between the reviewer's assessment of accuracy of a leaflet was high, with 89% (34/38) overall agreement. When considering those 30 leaflets judged inaccurate by one or other reviewer in order to calculate the specific inaccurate agreement rate, agreement fell slightly to 86% (26/30).

The major inaccuracies identified had a recurring theme, the failure to describe the range of treatment options and

alternative sources of help (Fig. 2). In addition, the expert reviewers spontaneously commented on characteristics, which were beyond accuracy, but which they considered undesirable, these included 'single product promotion', 'obvious advertising', 'very limited scope of information', 'economical with the truth', 'tendency to oversimplify' and 'inappropriate scary stories'.

Presentation and content

Leaflets scored on average 16 (median 14, mode 13, range 8–26) out of a maximum score of 35 (Fig. 3). Almost all leaflets scored highly on issues of presentation (size, layout, paper, typeface) (Table 3 and Table 4). Over half, stated the aims of the publication and were judged to have achieved these, including addressing quality-of-life issues. A minority of leaflets (16/38, 42%) was judged to contain information on all management and treatment options and only nine (24%) were thought to contain unbiased information. Rarely (less than 10%) did leaflets contain a glossary of terms, list other relevant publications or provide space for recording individual data or questions. Only two leaflets addressed uncertainties and gaps in evidence and none included any referenced statements. There was no explicit involvement of consumers in the development or refinement of the leaflets and the needs of non-English speakers did not appear to have been addressed.

Discussion

General

A total of 38 different leaflets for patients with hayfever were identified, but despite there being numerous publications for this condition, availability was patchy, even at the height of the hayfever season, and very few practices offered a wide choice of leaflets. The problem of availability may be further compounded by the often very informal approach to distribution, with leaflets displayed or left in piles rather than being handed to patients. It is recognized that information is more powerful when used as supplement rather than a substitute for good communication between the patient and the health professional. In discussion one can ascertain the patient's own beliefs, concerns and expectations and then indicate how the printed information matches their needs.

Hayfever is a disease that is very common in children and adolescents. A recent study found a lifetime prevalence of 23.7% amongst 13- and 14-year-old schoolchildren [12] and yet all the leaflets were assessed as being aimed at adults. The absence of leaflets for children and adolescents and the unavailability of leaflets in a language other than English contrasted with our earlier review of leaflets for asthma [4].

Five and a half million people in Britain have reading difficulties [13] and considerably more (22% of the working population) have a low level of literacy. Text with SMOG scores under 5 will be understood by most people and it is recommended that health literature should be written at SMOG score less than or equal to 5 [14]. In this study, the lowest scoring leaflet was scored at 9. Eighty-three per cent of leaflets assessed would only be understandable by those

Minor inaccuracies

Quote from leaflet	Experts' comment
<i>'...desensitisation, which is a course of regular injections given by your own doctor or at the clinic</i>	These injections have not been available in General Practice in the UK since 1986.
<i>'If these medicines fail, treatment with corticosteroid tablets may be given. A long acting injection is an alternative but more commonly causes side effects'</i>	An intramuscular injection of steroids is not recommended.
<i>'Avoid going out in the late evening and very early morning when the pollen count is highest.'</i>	Pollen counts peak as the morning progresses, and are not high initially.
<i>'... the biggest culprits are pollens from grasses, trees and flowers –especially oil seed rape.'</i>	Oil seed rape is a minor contributor to seasonal symptoms and when troublesome it is an irritant response to volatile organic compounds rather than allergy.
<i>'....an ioniser in your hotel room or bedroom can reduce the amount of pollen in the air'</i>	There is implied benefit in this statement which is unsupported by any evidence.

Major inaccuracies

Quote from leaflet	Experts' comment
<i>'Nobody but doctors has the right to prescribe medicines.....NEVER take medicine without consulting your doctor!'</i>	Most antihistamines, anti-inflammatory and decongestant nasal spray treatments can be bought without a prescription.
<i>'Whilst there is no known cure for hayfever and allergies the symptoms can be controlled very successfully. Many are available from your pharmacist; [these are] antihistamines and eye drops'</i>	No mention of nasal sprays or nasal corticosteroids. No mention of additional treatment options available after consultation with doctor, e.g. oral corticosteroids or desensitization.
<i>What can you do to relieve hayfever?</i> <i>'10. Talk to your pharmacist about modern antihistamine medicines. These can often stop or reduce the misery of hayfever symptoms'</i>	Ten tips are listed, but only one relates to medication. Implies that oral antihistamines are the only pharmacotherapy available.

Fig. 2. Examples of inaccurate information included in patient information leaflets published for people with hayfever.

who have completed secondary education. Understanding the remaining 17% would require tertiary education. Two leaflets had a score comparable with recent editorials in Clinical and Experimental Allergy. Other studies have found similar problems with the readability of information leaflets for other conditions [15,16].

Accuracy

Assessments of readability have frequently been used to describe the quality of patient information leaflets but it is arguable that accuracy is more important. The accuracy of the information within these leaflets was found to be very variable. Eight leaflets had no inaccuracies but one leaflet had three minor and one major factual inaccuracy. The level of inaccuracy was higher than that found in a comparable study of asthma leaflets [4], but as in that study, none of the

inaccuracies would have endangered or posed a serious threat to a patient's well-being.

Bias

The objective criterion-based assessment and the unstructured feedback from the allergy experts both identified concerns about bias in the presentation and content of leaflets. Concern about the representation of information being distorted by commercial interests is not new, for example, it has been well-rehearsed in the field of infant feeding [17] and weaning [18]. In many of the hayfever leaflets companies gave undue prominence to their own products. The use of brand names and failure to acknowledge the full armamentarium of pharmaceutical agents make educational materials 'nothing but thinly disguised advertising vehicles' [19]. Instead of

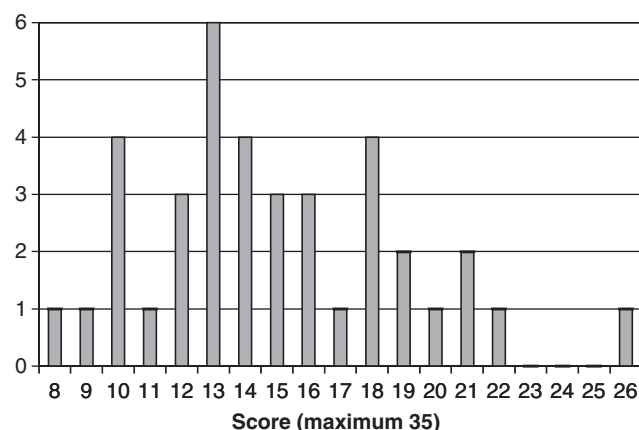


Fig. 3. Distribution of leaflet scores.

empowering the patient and enhancing their choice, such leaflets systematically favour only one model of care.

Study limitations

We have used the term patients in this paper as it is the most commonly used in clinical settings, but we recognize that alternative terms may be more appropriate, such as customer, user, and consumer, particularly for those people accessing information from a community pharmacy. This evaluation did not include the voice of patients, but represents the views of primary care health professionals (nurses, GPs and pharmacists) and allergy specialists. While they are well-placed to judge completeness and accuracy of the information, this approach assumes that the interests, needs and priorities of professionals coincide with those of patients and risks consideration of patients as a homogenous group, forgetting that different patients require different amounts and types of information to cope, and that their need for information may vary at different times in the course of their illness. The targeting and appropriate use of health promotion literature for different individuals is important [20], providing patients with a selection enables them to choose the level and amount of information, which best fits with their coping behaviour and information needs at that time.

Readability formulae have limitations. They are a proxy measure of readability and ideally testing should be done with patients, as reading is a complex process and ability to comprehend a text is influenced by presentation, organization, print, illustration, situation, stress, and reader characteristics (motivation, maturity). Formulae based on word length disregard patient's familiarity with the vocabulary associated with their illness, and may thereby over estimate the difficulty of the text. Formulaic assessments also mask the variability of reading ages within the same text [21].

The proportion of pharmacists and practices wishing to participate in this research was 43%, somewhat less than ideal, but considerably better than the response rate to many community-based studies. It is likely that the practitioners willing to participate were more interested in allergy than the non-responders and, therefore, we would postulate that these results may tend to overestimate the amount and quality of information generally available to people with hayfever.

Table 3. BMA patient information appraisal criteria

	Number meeting criterion	Percentage meeting criterion
Appropriate size	36	94.7
Content appropriate to readership	36	94.7
Clear language and appropriate tone	35	92.1
Good-quality paper	33	86.8
Appropriate typeface	33	86.8
Clear explanation of condition	31	81.6
Good layout	30	78.9
Clear information on source organization	30	78.9
Good use of colour	28	73.7
Layout enhances accessibility of contents	25	65.8
Addresses quality of life issues	25	65.8
Target readership clearly stated	25	65.8
Aims clearly stated	24	63.2
Achieves stated aims	24	63.2
No bias towards one particular treatment	20	52.6
Includes key points section	17	44.7
Clear statement of authors and agencies involved	16	42.1
Suggestions for further reading or contact addresses	16	42.1
Information on all treatment/management options	16	42.1
Likely to enhance shared decision making	14	36.8
Date of production or revision stated	11	28.9
Unbiased information	9	23.7
Contents page	8	21.1
Professional involvement in leaflet development	7	18.4
NHS journey described	7	18.4
Includes case studies or patient anecdotes	4	10.5
Lists other leaflets by same organisation	3	7.9
Glossary of terms	2	5.3
Addresses uncertainties and gaps in evidence	2	5.3
Space for recording personal information or questions	1	2.6
Caters for different cultures and religious beliefs	0	0
Provision for non-English speakers	0	0
User involvement in leaflet development	0	0
Includes feedback form for user comment	0	0
Includes referenced statements	0	0

Summary

A large number of leaflets are published for people with hayfever, but they are of variable quality and not accessible to all patients because of limited distribution and high readability scores. Rather than attempting wholesale revision of the leaflets available, it is more realistic to match readers with

Table 4. Further details of those leaflets judged highly for accuracy, presentation and readability

Hayfever, Doctor Direct Ltd, 1998.
Avoiding Allergens, Doctor Direct Ltd, 1998.
<i>These two leaflets are concise and accurate. Their clarity has been approved by the Plain English Campaign.</i>
Allergies, Medicom UK Ltd, 1998.
<i>Provides a brief overview of allergies including hayfever. Accurate content and scores highly on presentation style.</i>
Allergies – The More You Know The Less You Suffer. UCB Institute of Allergy, 1994.
<i>Lots of unbiased information presented in a 64-page small booklet form. Moderate readability.</i>
Hay fever – What It Is And How To Cope, Allen & Hanbury, 1993.
<i>This small booklet scores highly on presentation and accuracy. It is not biased towards company's own products. Slightly out-dated section on immunotherapy.</i>
Asthma and Hayfever, National Asthma Campaign, 1997.
<i>Excellent presentation. This version includes out-dated information on over the counter medications but is otherwise accurate. Moderate readability.</i>

the most appropriate existing materials and to strive for low readability scores in replacement leaflets. The authors and publishers of future leaflets need to follow published guidelines on leaflet production [9–11] especially regarding contents if patients are to derive maximum benefit from written information. In the absence of a national public health information strategy or a body that systematically vets patient information materials, clinicians must be vigilant in reading leaflets and assessing the quality of information provided for patients both within and outside their consultations.

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