Barriers to patient information provision in primary care: patients' and general practitioners' experiences and expectations of information for low back pain

Aileen McIntosh BA (Hons) MSc MPhil and Clare F M Shaw BA (Hons) MSc

Public Health, School of Health and Related Research, Sheffield, UK

Correspondence
Aileen McIntosh
School of Health and Related Research
University of Sheffield
Regent Court
30 Regent Street
Sheffield S1 4DA
UK
E-mail: a.mcintosh@sheffield.ac.uk

Accepted for publication
28 August 2002

Keywords: low back pain, patient information, doctor–patient communication, quality assessment

Abstract

Background As patient involvement in health-care increases, the role of information is crucial, especially in conditions where self-management is considered an integral part of care. However, the suitability and applicability of much patient information has not been appraised in terms of how far it meets patients' information needs.

Aims To ascertain patients' and clinicians' experiences and expectations of information in low back pain in order to suggest a suitable 'patient-centred' content for a patient information pack to be used in a primary care setting.

Methods A qualitative study using semi-structured interviews with General Practitioners (GPs) ($n = 15$) and focus groups comprising patients with low back pain ($n = 37$).

Results Barriers to information-giving for low back pain in primary care exist. Patients are dissatisfied with the information they receive from their GPs, especially regarding diagnosis and treatment. Patients tend to access information from a variety of other sources, which is often contradictory, conflicts with research evidence and leads to unreasonable expectations. GPs have varying views regarding the value of patient information and are equivocal about their roles as information providers. Although *The Back Book* is generally acceptable as a patient information leaflet for low back pain, attention to the tone of the text is required.

Conclusions Barriers exist to patient information provision, both generally and for low back pain, which need to be addressed in order to close the gap between strategy and implementation. Improving clinician communication skills and involving patients in developing information materials which meet their needs are crucial to this process.

Background

The promotion of patient advocacy and empowerment has been a marked feature of the UK National Health Service (NHS) agenda since the 1980s, reflecting the rise of consumerism and the notion of 'consumer sovereignty' in health-care decision-making. The provision by health-care professionals of good quality patient information, information that is evidence-based and developed with the involvement of patients and the public, has been seen as crucial to this process.[1,2] These policy initiatives are clearly predicated on the promotion of the 'patient-centred' approach to information and education, which emphasizes the priorities and needs of patients, and perceives printed information as a means of empowering patients rather than correcting them. This preferred agenda contrasts with the hitherto dominant 'medico-centred' agenda, which predicates on outcomes that are important from a biomedical perspective, and on an assumption of patient passivity and compliance.[3,4] Moreover, these strategies have explicitly linked the provision of patient information materials to improved health outcomes, an association borne out by a small body of research evidence, especially in conditions where self-management is considered an integral part of care.[5–7]

In response to this policy agenda there has been a rapid, largely unregulated, expansion in patient information materials over recent years, such as leaflets, books, videos and web-based technology, designed, for instance, to promote healthy lifestyles and to educate patients in the self-management of chronic conditions. Sources of these types of materials have included GP practices, hospital trusts, drug companies and charitable organizations. This largely uncontrolled development in information materials has, however, given rise to concerns about the accessibility, quality, content and suitability of some of these materials in meeting the needs of the patient.[8–13] Despite the clear message from the Department of Health to establish patients' information needs '*in a strategic, systematic way*' by eliciting their views and feedback,[1] there appears to be scant research evidence which explores why patients want certain types of information and what use they make of such materials.[13–15]

In view of the general lack of research evidence which explores or evaluates patients' information needs and the use they make of information, coupled with the evidence which points to the positive effect patient information and education appears to have on a range of health behaviours and outcomes, this study evaluated the condition of low back pain as an exemplary model upon which to assess the impact of patient information.

Despite its acknowledgement as a largely benign '*everyday bodily symptom*,'[16] amenable to primary care management and patient self-care, low back pain represents an escalating and costly problem in terms of use of health-care services, disability and work loss.[17,18] Maniadakis and Gray quote figures for 1997 which report that 12–16% of all adults visited their GP annually with back pain. For 1998, they estimate that the total cost of care relating to back pain in primary care in the UK was £140.6 million, and they quote social security figures for 1994–95 revealing that 116 million production days were lost because of back pain morbidity. Estimates of the proportion of people with low back pain who go on to develop chronic low back pain (usually defined as pain lasting more than 12 weeks) may be as high as 29%.[19]

That patient information may have a role to play in addressing this low back pain 'epidemic' has been recognized;[19] indeed, there is some research evidence to suggest that patient educational materials can alter knowledge and behaviours in patients with low back pain,[20] reduce secondary care referrals and hospital admission,[21] and have a positive effect on patients' beliefs and clinical outcomes.[22] However, reflecting the wider consensus, there have been concerns about the quality and suitability of patient information materials for low back pain.[12,23,24] Indeed, despite the production of an evidence-based patient information leaflet, *The Back Book*,[25] based on the Royal College of General Practitioners' clinical guidelines for the management of acute low back pain[26] (AM was one of the guideline developers), it has been noted that patients were not directly involved in the development of the leaflet.[12]

Therefore, using the condition of low back pain as a ‘patient information model’, we conducted this study to ascertain patients’ information needs from the perspectives of both patients and their GPs in order to suggest a suitable content for a patient information pack to be distributed to patients presenting in a primary care setting with acute low back pain.

Methods

Design

The study design employed qualitative research methods, involving one-to-one semi-structured interviews with GPs and focus groups of patients who were low back pain sufferers. Semi-structured interviews, rather than focus groups, were chosen as the most practical method of eliciting GPs’ views on low back pain information issues due to the wide geographical spread of the individual volunteering GPs and to the time-scales of the study. However, we used focus groups of low back pain patients as their organization was more easily conducted based upon discrete practice populations.

Whilst quantitative methods, such as postal questionnaires, could have been used as a data collection method, a qualitative approach was felt to be more appropriate to provide a detailed investigation of the ‘real life’ experiences and views of the study participants; what has been termed ‘*information-rich*’ data.[27]

Recruitment and sampling

We approached three primary care research networks to assist us in recruiting GPs and patients from their practice lists from four study sites: East Riding and Tees Health Authority (HA) districts (Northern & Yorkshire region) and South Humber and Sheffield HA districts (Trent region). The rationale for the sampling approaches was purposive in origin (a range of GPs in terms of geographical location and a selected group of their patients with low back pain), although recruitment into the study was ultimately influenced in terms of convenience by GP and patient self-selection, and by resource considerations on the part of the researchers. GPs were contacted initially by post, inviting them to take part in the study. Several of the recruited GPs were asked to contact patients from their practice lists on our behalf for possible participation in focus group meetings. Patients to be approached for inclusion in the study were those aged between 25 and 64 years, who had consulted their GP for low back pain during the previous 12 months, were able to read, understand and speak English, and had not been involved in other back pain studies in recent years.

Participant characteristics

Fifteen GPs participated in the interviews: three from East Riding HA, six from Tees HA and six from Trent. Practices and practice populations reflected a wide spread in terms of location and socio-economic status.

Thirty-seven patients from the practice lists of four of the recruited GPs took part in six focus group meetings (one group of six patients from East Riding HA, one group of eight patients from Tees HA and four groups of four, five, six and eight patients from Trent). Socio-economic status of participants was varied, with the highest numbers of patients being assigned to social classes 1.2, 3 and 7 (higher managerial, intermediate and routine occupations, respectively*). Almost two-thirds (65%) of patients had left school aged 15 or 16 years having gained either no qualifications ($n = 9$) or CSEs/GCEs/secretarial qualifications ($n = 15$).

Slightly more than half of the patients ($n = 19$ or 51%) reported having had 10 or more bouts of low back pain in their lives, and more than one-third complained of ongoing or constant low back pain. The majority of patients stated that low back pain had had an effect on their capacity to work ($n = 27$ or 73%) and on their lives in general ($n = 31$ or 84%). The treatments which patients had tried included drugs, physiotherapy,

---

*Classification according to the National Statistics Socio-Economic Status Classification, 2001.

osteopathy and chiropractic, with four patients having had surgery for low back pain.

GP interview procedure and materials

Interviews that took place at GP surgeries were audiotaped and generally lasted between 30 and 45 minutes. During the interviews, a semi-structured interview schedule was used to question GPs about their current management of patients with acute low back pain, what information and advice they gave to such patients, and what they felt patients needed to know about low back pain. The GPs were also asked their opinions of the patient information booklet, *The Back Book*, and to what extent they felt that it was representative of an 'ideal' information leaflet to give to patients with acute low back pain. Following the interviews, GPs were asked to complete a short demographic questionnaire.

Focus group procedure and materials

The focus group meetings took place at a 'neutral' location (that is, on non-GP practice premises) convenient for local patients to attend. Prior to the focus group discussions, participants were asked to complete a demographic questionnaire. All the focus groups were facilitated by one of the researchers (CS), were audiotaped and generally lasted between 1 and 1.5 hours. Participants were asked to reflect on the word 'information' to clarify the scope of its interpretation. They were then asked about types and amount of information they had received during the course of their low back pain, about the sources of the information they had received, and about what information they felt they needed. Participants were also asked to give their opinions of the patient information booklet, *The Back Book*, which they had been sent before the meeting.

Data analysis

The tape recordings of GP interviews and the focus group meetings were transcribed verbatim. Data from both sets of transcriptions were analysed following the 'Framework' analysis method as described by Ritchie and Spencer.[28] This qualitative data analysis technique was used due to its appropriateness for applied policy research, whereby research objectives are clearly defined and any output from the research is targeted towards providing explanations and actionable outcomes.

Data from the two data sets were analysed separately (GP and focus group transcriptions), although associations across both sets of data were sought at the mapping and interpretation stage of the analysis. In order to ensure the reliability of the analysis, samples from both sets of transcripts were read independently by both researchers (AM and CS), and agreement on the thematic framework reached, prior to the coding of data.

The responses from the demographic questionnaires were analysed using the Statistical Package for the Social Sciences (SPSS Inc., Cary, NJ, USA), Version 10.0.

Ethical approval and participant consent

Ethical approval was granted for the study from Trent Multi-Centre Research Ethics Committee, and from all local research ethics committees covering the localities where the study took place. Patients and GPs gave their consent to take part in the study and to the audiotaping of the focus group meetings and interviews, respectively.

Results and discussion

The purpose of this study was to determine what patients' information needs were in low back pain in order to suggest a suitable 'patient-centred' content for a patient information pack for use in a primary care setting. In exploring the responses of both patients and their GPs, a number of issues were raised which would suggest that fulfilling patients' information needs in low back pain is not a straightforward process.

Patients and GPs have differing views on the value of patient information materials

Patients reported almost exclusively having received little or no information of any type from their GPs. Patients considered this a highly frustrating situation because they valued, and were particularly eager for, information that would help them deal with their back pain themselves, and also were prepared to make behavioural changes which might help alleviate their symptoms as a result. As these two women stated:

> I feel more in control the more knowledge I have, the better I feel, because I feel that I've got something that I can sink my teeth into. (Female aged 38, sewing machinist)

> If I know what exercises to try to do to strengthen [my back], I can maybe try to alter how I do the things and hopefully my back won't be as bad as it is and I can carry on with [my] job. (Female aged 45, nurse)

In contrast, whilst all the GPs interviewed spoke of providing verbal information about low back pain to their patients, viewing it as an integral element of doctor–patient communication, they had, however, quite differing views on the value of patient information materials. Although some felt that they were essential components of the consultation in that they reinforced the GP's verbal advice and led to improved health outcomes, others felt that either their value had yet to be proved or that patients discarded leaflets because of lack of aptitude or time to read them. As one GP commented:

> There's the worry that … the more information you give out, sometimes its not going to get read … One or two lines of messages is all that most patients can cope with. (Male GP aged 43)

Also a minority of GPs mentioned that, although they believed information materials to be generally of benefit to patients, they were unsure of their value for patients with low back pain; and one GP, in particular, considered that patient information materials such as *The Back Book* would only serve to 'medicalize' low back pain – confer 'disease' status to what was a essentially a benign symptom:

> [*The Back Book*] is a form of words that provide an explanation, OK, but it's already medicalizing a problem. It's saying you have a bad back, sorry, your tests are normal … and we don't really know why it's bad but, you know, we think it's muscles and ligaments and joints, you know. It's kind of little mysterious things going on inside, so this is a form of medicalisation. Congratulations, you haven't got a bad back, but actually congratulations, you have got a bad back without a serious cause. (Male GP aged 49)

Thus, although patient information materials, especially those designed for self-manageable conditions such as low back pain, have been viewed as an important element in the achievement of a 'patient-centred' approach to health-care provision,[1,2] a useful adjunct to verbal advice[1], and in demand by patients in this study, it would appear that some GPs are reluctant to distribute them to their patients. This finding would tend to suggest that patients have been experiencing, and are likely to continue to experience, inequity in terms of what information materials they receive. Furthermore, many of the GPs who supported the provision of patient information materials were, however, equivocal about their responsibilities as information providers, mentioning problems with finance, prioritization and time factors. As this GP reflects:

> I've only got one [leaflet for low back pain], I've only got the exercises one … there is stuff that comes through, general back pain … I know all of these are available, but as a practice we don't have a fund to buy outside books and stuff like that. (Female GP aged 37)

This confirms previous research which suggests that health-care professionals view patient information as a 'desirable but peripheral' commodity, and not necessarily within their own discrete remit.[29]

Poor communication of diagnostic uncertainty

A major cause of discontent and frustration voiced by many of the patients was that their GPs had not provided them with an explicit 'diagnosis'; indeed, none of the patients appeared to have any conception or understanding of the problem of diagnostic uncertainty in low back pain:

> What worries me is that, as far as I'm concerned, if you've got a pain, your body is telling you that there's something wrong. You don't get a pain for no reason. So I don't understand just giving you a painkiller is going to cure the problem and this is what I got for years and years from the doctor: 'just take a painkiller, it will go away'. But every time I said, but why am I getting the pain? They can't answer that question, because they're not prepared to give you a diagnosis. (Female aged 42, auditor)

Whilst patient dissatisfaction with the adequacy of GPs' explanations of back pain has been previously reported[30–32] it is acknowledged that GPs are limited, certainly in terms of definitive diagnosis, in what they are able to offer the low back pain patient, predicated on their knowledge of low back pain as a largely benign, self-limiting condition.[16] Despite this admission on the part of the medical profession, most GPs interviewed in this study appear not to be acknowledging, or not adequately dealing with, the considerable problem that diagnostic uncertainty causes for many of their low back pain patients. Only one GP refers to this problem directly:

> It's partly why I think the NHS is groaning at the edges, people expect to have [a] proper diagnosis made, proper treatments given, but, you know, for the majority of problems we see, 70% of problems seen in general practice don't have pathological diagnoses or fixed treatment … I mean, if you came to see me with back pain and I examined you and said, 'well, you've got back pain', I'm not sure quite how satisfied you would be. (Male GP aged 49)

Reflecting research findings reported elsewhere,[33–36] patients in this study appear to associate GPs' perceived lack of diagnostic certainty with assumptions that the GP is either unable to help, or believes them to be malingering, and is thus withholding diagnostic information and access to more specialized back pain services:

> I think [GPs are] sympathetic, but they just can't do it … they haven't got the qualifications to give massage or manipulation – all they've got is their pen. (Male aged 39, crane driver)

> One GP thought I was malingering and said 'don't you like your work or are you just getting signed off sick?' I was very annoyed at that because I happened really to enjoy my work. I worked full-time and the last thing I needed at that time was to be off sick, it was very inconvenient. I found that an atrocious attitude. (Female aged 63, retired)

Indeed, some of the more chronic back pain sufferers in this study, in their perceived confusion and uncertainty about diagnosis and treatment, appear to blame their ill-health on their GPs, and some have even financed tests and surgery themselves in the search for a diagnostic solution. May *et al.*[35] believe that these types of responses from chronic low back pain sufferers should be understood as '*rational responses to clinical doubt and uncertainty*' and contend that clinical attention should be more sympathetically focused towards an understanding of patients' perceptions of responsibility and potential for recovery in low back pain. Certainly, it would appear that attempts at gaining a greater understanding of patients' health beliefs, experiences and behaviours is warranted, as well as improved doctor–patient communication about the nature of the problem.

Information and advice is often conflicting

Although patients reported receiving virtually no information from their GPs, they did access alternative sources of information and treatment for low back pain, for instance, from other health-care professionals such as physiotherapists, osteopaths and chiropractors, and other sources such as family and friends, magazines, the television and the Internet. Patients seemed to find the information received or obtained from these sources particularly important – as though 'any information is better than none'. They were, however, aware that the information and advice they received was often conflicting, and for some patients, this raised the difficulty of being able to assess which information was valid and trustworthy. One man had refused to read *The Back Book*, which had been sent to all focus group participants prior to the meetings, because he disputed its validity:

> Is it the correct advice, though? … I didn't read [The Back Book] because it's just another piece of paper that's telling me something that may, or may not, be right. (Male aged 39, crane driver)

The issue of conflicting information and advice also causes problems in terms of encouraging, what some GPs feel are, unreasonable expectations and beliefs in their patients; for instance, as one GP graphically reflected:

> You get people who come in saying, you know, I've been told by my chiropractor that my spine is out of alignment and it needs to be realigned, and can you arrange for it to be realigned. Where do you start? I mean, a consultation like that just sort of kills me. (Male GP aged 49)

Indeed, more than half the GPs considered that low back pain patients had numerous misconceptions and personal fears about low back pain; that they often came '*with their own agendas*'. Examples of these 'agendas' included beliefs that they had a disc lesion; that they needed bed rest; that they would become crippled by their back pain; or that they needed unnecessary investigations, such as X-rays:

> Well, a lot of them have got a perception [that] X-ray would show things, how they are getting the back problem, and I have to tell them time and time again, the X-ray actually will not show anything really, but this is the perception – it's generalised. Most of them ask for an X-ray because they think it is a miracle diagnostic tool. It is not. (Male GP aged 58)

There was also some acknowledgement amongst GPs that part of the problem of patients' 'unreasonable' expectations was associated with the recent fundamental change in advice for the management of acute low back pain:

> It's confusing enough now when 10 years ago you were told to go to bed for 3 weeks. But now we say, the last thing you do is go to bed. So patients do get a bit confused … and nowhere is this more relevant than back pain – patients with corsets … who've worn them for 25 years, and you can't say, 'well, sorry, we don't want you to wear them – for the last 25 years you've been doing something [which] is harmful'! (Male GP aged 44)

This problem of coping with conflicting and changing information and the impact it has on patients' expectations and beliefs appears to hinge on ensuring that evidence-based health information is promoted as carrying the 'optimum' health advice. As Entwistle and O'Donnell[37] note, patients may rate other types of evidence and information, such as their own or friends' experiences or what is reported in the media, as more credible or important than 'conventional' research evidence. They maintain that the means to improve this situation and to enhance the potential of evidence-based healthcare lies in fully involving patients, or consumers, in the generation of research evidence and production of information materials.

Appraisal of *The Back Book*

GPs and patients were asked to appraise *The Back Book*, an information leaflet based on up-to-date research evidence and designed to be distributed to acute low back pain patients in a primary care setting. Confirming the findings of earlier research,[38] the majority of GPs and patients in this study felt on the whole that *The Back Book* was well-written, readable, positive, contained the 'right' messages and measured up well to what they believed was an 'ideal' patient information leaflet for low back pain; as one patient commented:

> When I read [*The Back Book*] I thought, well, why didn't I get something like that? (Female aged 53, secretary)

Although many of the patients appeared to be chronic low back pain sufferers, most believed that, had they been given *The Back Book* at an acute, or earlier, stage, it would have helped them to cope with their back pain themselves and may have prevented their back pain reaching a chronic stage, for example:

> I think I'd have made more positive efforts to stay more active over the last couple of years, because obviously that's one of the messages. (Male aged 42, research chemist)

This finding also supports a number of previous studies which have found that low back pain patients are keen to obtain information and advice on self-help and how to return to normal activities.[12,39,40]

However, despite the evidence-based nature of *The Back Book*, particular reservations of a subset of patients from two of the six focus groups in this study, and similarly of patients in Coulter *et al.*'s report,[12] were that the tone of the leaflet's text was patronising and that its labelling of low back pain sufferers as either 'copers' or 'avoiders' categorized low back pain patients unfairly:

> I found it quite condescending. I mean, I don't think, you know, any intelligent human being suffering acute back pain could be called either a coper or an avoider. (Female aged 38, sewing machinist)

> What annoyed me is things like this one: 'avoiders suffer the most pain for longer, then have more time off work and then become disabled'. Well, I thought, well, you know, alright I am [disabled], but I didn't want to be this way and I thought that the way I read this was, oh, that we want to be that way. (Male aged 43, permanently sick/disabled)

This finding, moreover, appears to confirm Dixon-Woods'[4] identification of the dichotomy in discursive strategies contained in patient information leaflets, in that *The Back Book* exemplifies a 'professional-driven' or medico-centred discourse in its characterization of patients in an unflattering and limited way. However, reporting on the results of a small unpublished study carried out in 1996,[41] Wright found that by changing the tone of the text of *The Back Book*, the booklet's key messages were found to be significantly more acceptable. This was achieved by replacing long words with shorter alternatives, modifying sentence syntax by replacing imperatives with declaratives and re-sequencing the text to show sympathy for back pain sufferers before advocating change. Also, notably, all reference to the 'coper' and 'avoider' categorization was removed, replacing it instead with a more positive approach in terms of 'good' and 'bad' ideas to consider for those with back pain. By paying careful attention to the tone of the text in this way, Wright suggests that patients may be more willing to heed the advice contained in patient information leaflets. Moreover, this finding would suggest that ensuring that patient information materials are evidence-based, and fulfil various quality criteria such as legibility, readability and reliability[42] is inadequate: emphasis must also be placed on ensuring that the tone and language of the leaflet does not patronize or blame the potential reader – and involving patients in all stages of production is a key element in achieving this.

Limitations of the study

The study has limitations in terms of sampling methods. Purposive, or theoretical, sampling has been viewed as the preferred sampling method within qualitative research in that its objective of developing theory or explanation iteratively guides the sampling and data-collection processes, and enables the researcher to have some control over the diversity of a particular population.[43,44] However, problems with access to the study populations in our study and the necessity, in view of timescales, to accept those GPs and patients who had volunteered to take part, made such an approach difficult and gave less control than was desirable. In this respect, only a few female GPs took part in the study and focus group participants were predominantly female and exclusively white. Furthermore, many of the focus group participants appeared to be suffering, or had suffered in the past, from chronic low back pain, which may have had a bearing on their reactions to *The Back Book*, a leaflet specifically designed for patients with acute low back pain. The findings may therefore be subject to selection bias and may not necessarily be representative of a wider population of GPs, and patients with low back pain. Taking these limitations into consideration, however, a number of conclusions may still be drawn from the study.

Conclusions

Whilst patients in this study are keen to receive as much information as possible from their GPs on how to care for their low back pain themselves, they remain highly dissatisfied with the amount and quality of information and advice that they receive, particularly regarding diagnosis and treatment. Patients appear, furthermore, to be experiencing inequitable access to patient information materials, with some GPs valuing and supporting their use, whilst others question their value or believe that they may promote the 'medicalization' of low back pain. More equitable access to patient information materials which adequately address diagnostic and treatment uncertainties in low back pain, and improved clinician communication skills, are crucial if these types of problems are to be overcome.

More generally, there appears to be confusion amongst GPs about who bears the responsibility for the routine provision of patient information, particularly in terms of the prioritization and funding of information materials. Clarification on the responsibilities of health-care professionals to provide patient information materials and on overall resource issues is urgently needed.

Conflicting and changing health-care advice causes problems for both patients and GPs in terms of assessment of validity and potential adverse effects on health expectations and beliefs. The production and extensive promotion of regularly updated, evidence-based patient information materials whose design and development have involved the direct input of patients is essential to counteract these problems.

Lastly, *The Back Book*, as a patient information leaflet for acute low back pain, appears to be acceptable to GPs and, on the whole, to fulfil the information needs of patients. However, modifying the tone and language of the booklet in terms of ensuring that it is more 'patient-centred' is likely to enhance its' acceptability to patients, and an assessment of the suitability of an amended version of the booklet should be undertaken. Checklists for assessing the quality of patient information leaflets should include a measure for the tone and language of the text.

This study has thus identified a number of barriers to patient information provision, both in general and specifically with regard to low back pain. Addressing these barriers will prove essential if successful implementation of government strategies for a 'patient-centred' approach to information provision is to be achieved.

Acknowledgements

We thank the Northern Primary Care Research Network (NoReN), the Trent Focus Group and the Wolds Primary Care Research Network (WoReN) for their assistance with recruitment of GPs; all the GPs and patients who took part in interviews and focus group meetings; and GP practice managers and other administrative staff who identified patients from practice records and contacted them on our behalf. We also thank Oona Hunt who gave us secretarial and administrative support on the project; and Dr Alan Breen, Director, Institute for Musculoskeletal Research and Clinical Implementation, AECC, and Dr Jean Peters, Senior Lecturer, Public Health, ScHARR, University of Sheffield, for their helpful comments on earlier drafts. Funding for this study was provided by the NHS National R & D Primary/Secondary Care Interface Programme.

References

1 NHS Executive. *Patient Partnership: Building a Collaborative Strategy*. Leeds: NHS Executive Quality and Consumers Branch, 1996.

2 Department of Health. *Patient and Public Involvement in the New NHS*. London: The Stationery Office, 1999.

3 Fahrenfort M. Patient emancipation by health education: an impossible goal? *Patient Education and Counseling*, 1987; **10:** 25–37.

4 Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Social Science and Medicine*, 2001; **52:** 1417–1432.

5 Barlow JH, Turner AP, Wright CC. Long-term outcomes of an arthritis self-management programme. *British Journal of Rheumatology*, 1998; **37:** 1315–1319.

6 Clark NM, Nothwehr F. Self-management of asthma by adult patients. *Patient Education and Counseling*, 1997; **32** (Suppl. 1)**:** S5–S20.

7 Brown SA. Effects of educational interventions in diabetes care: a meta-analysis of findings. *Nursing Research*, 1998; **37:** 223–230.

8 Audit Commission. *What Seems to Be the Matter: Communication Between Hospitals and Patients*. London: HMSO, 1993.

9 Coulter A. Assembling the evidence: patient-focused outcomes research. *Health Libraries Review*, 1994; **11:** 263–268.

10 Meredith P, Emberton M, Wood C, Smith J. Comparison of patients' needs for information on prostate surgery with printed materials provided by surgeons. *Quality in Healthcare*, 1995; **4:** 18–23.

11 Smith H, Gooding S, Brown R, Frew A. Evaluation of readability and accuracy of information leaflets in general practice for patients with asthma. *British Medical Journal*, 1998; **317:** 264–265.

12 Coulter A, Entwistle V, Gilbert D. *Informing Patients: an Assessment of the Quality of Patient Information Materials*. London: King's Fund, 1998.

13 Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *British Medical Journal*, 1999; **318:** 318–322.

14 Donovan JL, Blake DR, Fleming WG. The patient is not a blank sheet. lay beliefs and their relevance to patient education. *British Journal of Rheumatology*, 1989; **28:** 58–61.

15 Olszewski D, Jones L. *Putting People in the Picture. Information for Patients and the Public About Illness and Treatment: a Review of the Literature*. Scottish Association of Health Councils, 1998.

16 Waddell G. Low neck pain. A twentieth century health-care enigma. *Spine*, 1996; **21:** 2820–2825.

17 Maniadakis N, Gray A. The economic burden of back pain in the UK. *Pain*, 2000; **84:** 95–103.

18 Palmer KT, Walsh K, Bendall H, Cooper C, Coggon D. Back pain in Britain. comparison of two prevalence surveys at an interval of 10 years. *British Medical Journal*, 2000; **320:** 1577–1578.

19 Evans G, Richards S. *Low Back Pain: an Evaluation of Therapeutic Interventions*. University of Bristol: Health-care Evaluation Unit: University of Bristol, 1996.

20 Roland M, Dixon M. Randomized controlled trial of an educational booklet for patients presenting with back pain in general practice. *Journal of the Royal College of General Practitioners*, 1989; **39:** 244–246.

21 Symonds TL, Burton AK, Tillotson KM, Main CJ. Absence resulting from low back trouble can be reduced by psychosocial intervention at the work place. *Spine*, 1995; **20:** 2738–2745.

22 Burton AK, Waddell G, Tillotson KM, Summerton N. Information and advice to patients with back pain can have a positive effect: a randomized controlled trial of a novel educational booklet in primary care. *Spine*, 1999; **24:** 2484–2491.

23 Clinical Standards Advisory Group (CSAG). *Epidemiology Review: the Epidemiology and Cost of Back Pai.N*. London: HMSO, 1994.

24 Buckland S, Christopher F. Public awareness and knowledge of methods for preventing and treating low back pain and how people deal with conflicting advice and uncertainty. Winchester: The Help for Health Trust, 1997.

25 Anonymous. *The Back Book*. London: The Stationery Office, 1996.

26 Waddell G, McIntosh A, Hutchinson A, Feder G, Lewis M. *Low Back Pain Evidence Review*. London: Royal College of General Practitioners, 1999.

27 Miles MB, Huberman AM. *Qualitative Data Analysis: an Expanded Sourcebook*, 2nd edn. Newbury Park, CA: Sage, 1994.

28 Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG (eds). *Analyzing Qualitative Data*. London: Routledge, 1994: 173–194.

29 Smith C. The role of health professionals in informing cancer patients: findings from The Teamwork Project (phase one). *Health Expectations*, 2000; **3:** 217–219.

30 Deyo RA, Diehl AK. Patient satisfaction with medical care for low-back pain. *Spine*, 1986; **11:** 28–30.

31 Skelton AM, Murphy EA, Murphy RJ, O'Dowd TC. Patients' views of low back pain and its management in general practice. *British Journal of General Practice*, 1996; **46:** 153–156.

32 Klaber Moffett JA, Newbronner E, Waddell G, Croucher K, Spear S. Public perceptions about low back pain and its management: a gap between expectations and reality? *Health Expectations*, 2000; **3:** 161–168.

33 Chew CA, May CR. The benefits of back pain. *Family Practice*, 1997; **14:** 461–465.

34 Borkan J, Reis S, Hermoni D, Biderman A. Talking about the pain. a patient-centered study of low back pain in primary care. *Social Science and Medicine*, 1995; **40:** 977–988.

35 May CR, Rose MJ, Johnstone FCW. Dealing with doubt. How patients account for non-specific chronic low back pain. *Journal of Psychosomatic Research*, 2000; **49:** 223–225.

36 Walker J, Holloway I, Sofaer B. In the system. the lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain*, 1999; **80:** 621–628.

37 Entwistle V, O'Donnell M. Evidence-based healthcare: what roles for patients? In: Edwards A, Elwyn G (eds). *Evidence-Based Patient Choice: Inevitable or Impossible?* Oxford: Oxford University Press, 2001; 34–49.

38 Burton AK, Waddell G, Burtt R, Blair S. Patient educational material in the management of low back pain in primary care. *Bulletin – Hospital for Joint Diseases*, 1996; **55:** 138–141.

39 von Korff M, Barlow W, Cherkin D, Deyo RA. Effects of practice style in managing back pain. *Annals of Internal Medicine*, 1994; **12:** 187–195.

40 Turner JA, LeResche L, von Korff M, Ehrlich K. Back pain in primary care: patient characteristics, content of initial visit, and short-term outcomes. *Spine*, 1998; **23:** 463–469.

41 Wright P. *Parallel messages in press and other media for patient information*. Paper presented at the IDN Conference, Cambridge, 1997.

42 The Centre for Health Information Quality. *C-H-I-Q Guidelines*, 2001, http://www.hfht.org.chiq/appraisals_new.htm.

43 Mays N, Pope C (eds). *Qualitative Research in Healthcare*. London: BMJ Publishing Group, 1996.

44 Barbour RS. Checklists for improving rigour in qualitative research. a case of the tail wagging the dog? *British Medical Journal*, 2001; **322:** 1115–1117.