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Assessing the quality of information to support people in making decisions about their health and healthcare

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NOVEMBER 2006

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- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
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ISBN 1 905945 03 5

978 1 905945 03 0

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Published by and available from:

Picker Institute Europe
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Oxford OX1 1RX
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Acknowledgements

The Picker Institute was commissioned and funded by the Department of Health in England to carry out this research study.

We are most grateful to all those who helped with this study by kindly responding to our requests for information or by agreeing to be interviewed. Special thanks are due to Sarah Allen for her help in locating information materials and to Caroline Rose for her sterling work on the provider survey.

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Executive summary

1. A study was carried out to determine the current quality of health information and to assess the added value of accrediting information providers. The study consisted of four components:
a) a review of research evidence on patients' information needs and the effectiveness of providing health information;
b) a web search, a survey of health information specialists, and a statistical review to estimate the number of organisations providing health information;
c) a detailed assessment of 40 information materials; and
d) a telephone survey of information providers to obtain information on the development process.

2. An evidence-based checklist developed by the International Patient Decision Aid Standards (IPDAS) collaboration was used to assess a selected group of information materials in relation to their content and development process.

3. A majority of patients (80%) actively seek information about how to cope with health problems. While three-quarters cite their doctor as the most important source of health information, other sources are also used. For example, a third go to the internet, and a quarter look for information in leaflets and books. A wide variety of other sources are also used, including other professionals, family and friends, media and patient organisations.

4. Patient information is effective in improving patients' knowledge and recall of medical facts. Combining verbal and written information is more effective than verbal information alone and personalised computer-based information is more effective than general information. Many patients prefer health information that is delivered using audio, visual or interactive media. People in disadvantaged groups derive greater benefit from computer-based health information systems than those with higher levels of health literacy. Computer-based systems which combine information delivery with online discussion groups improve social support among people with chronic conditions. Computer-based systems can also have a positive effect on self-care. There is strong evidence for the effectiveness of patient decision aids, which improve both patients' knowledge and their realistic expectations of the benefits and harms of treatment. They also improve patients' involvement in decisions and the level of agreement between patients' values and treatments chosen, and in some cases they lead to reductions in resource use.

5. Our searches for providers of information on the four case-study topics (chronic obstructive pulmonary disease (COPD), arthritis, healthy eating/obesity, and measles, mumps and rubella (MMR) vaccination) yielded a total of 237 organisations. Of these, 43% were public sector organisations, 30% were commercial organisations and 27% came from the voluntary sector. The majority (87%) offered information on only one of the four topics.

6. Our estimate of the total number of organisations in the UK economy that provide health and social care information for patients and the public was 60,000, roughly a third of the number that had previously been estimated.

7. The revised IPDAS checklist proved to be a useful tool for assessing the quality of information materials. This revealed wide variations in quality: materials tended to score reasonably well on

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clarity of structure and layout, having a clear statement of aims and including information on the date of publication, but they performed significantly worse in relation to the provision of accurate, reliable and sufficiently detailed clinical information to assist patients in decision-making. In particular, few materials included a clear presentation of the likely outcomes of treatment, few mentioned clinical controversies or uncertainties, and many failed to acknowledge the patient's decision-making role.

8. Estimates of providers' annual expenditure on patient information materials ranged from £2,000 to £6,000,000. They also gave a wide range of estimates of the numbers of users of their information, ranging from 8,000 to 13.5 million per year. Most providers do not make direct charges for accessing their information materials, but some websites carry advertising.

9. Most provider organisations were committed to the concept of involving users in developing and evaluating their materials, but many had no systematic process for doing so. Similarly, most tried to ensure their material was evidence-based, but many contracted the writing to a single clinical 'expert', without supplying guidelines for the process of evidence review. Few had adopted systematic or rigorous strategies for assessing the readability and usability of their materials, and few had developed effective dissemination strategies. In some cases there were major discrepancies between the scores achieved for quality of information content and providers' accounts of the development process.

10. Most respondents reacted positively to the idea of an information accreditation scheme. Perceived advantages included raising quality standards in patient information provision, increased revenue for information providers, enhanced trust among health professionals, greater use of information by patients and the public, and improving the image of information providers. However, there were also some concerns about how the scheme would operate, including worries about the cost to providers and how time-consuming the application process might be, whether it would be sufficiently well advertised to command widespread recognition and respect, and whether it would be sufficiently flexible to encourage creativity.

Conclusions

- Good quality health information is essential for greater patient involvement in healthcare, but the quality of patient information materials needs to be improved.

- A key priority is to develop materials that include accurate, reliable and sufficiently detailed clinical information to help patients make treatment choices.

- It is not sufficient to rely on the knowledge and judgement of individual clinicians to write patient information materials. Authors must be given clear guidelines on how to review the evidence on what is known and not known about the effectiveness of treatments, and how to present this information to patients in a comprehensible way.

- Information provider organisations should be more systematic about involving patients and other stakeholders in developing and evaluating their materials.

- Greater attention needs to be paid to improving access to patient information materials so they can be used by patients and clinicians to inform their decisions.

- An information accreditation scheme could help to raise quality standards.

1 Introduction

Good quality health information is essential for greater patient involvement in healthcare. Patients and the public require information that is timely, relevant, reliable and easy to understand. This is an essential component of any strategy to promote health literacy, self-care, choice, shared decision-making, medication adherence and self-management of chronic disease. Patients have many decisions to make about their healthcare and, like all decision-makers, they require information to inform their choices. Reliable information is also essential to help patients understand their health problems and how to deal with them.

Unfortunately the quality of much health information produced for patients and the public is not reliable. A study published in 1999 (Coulter et al 1999), which involved an in-depth exploration of patients' information needs, together with an assessment of the quality of written and audio-visual information materials by patients and by expert clinicians, concluded that:

- The quality of most patient information materials was poor
- Patients wanted information about treatment options and outcomes even if they did not want to actively participate in treatment decisions, but most didn't receive it
- Many materials contained inaccurate and out-of-date information
- Topics of relevance to patients were often omitted
- Coverage of treatment options was often incomplete
- Information about treatment effectiveness was often missing or unreliable
- Few provided adequate information about treatment risks and side-effects
- Technical terms were not always clearly explained
- Uncertainties were ignored or glossed over
- Few materials actively promoted shared decision-making.

However, data collection for the study was carried out eight years ago and since then there has been a huge increase in the amount of information available, particularly on the internet. The decade has also seen a number of initiatives designed to promote improvements in the quality of patient information. Among these there has been considerable interest in the development of quality assessment and accreditation schemes to help guide people to reliable information.

The White Paper *Better Information, Better Choices, Better Health* proposed the development of a national information accreditation scheme to give members of the public "a clear set of quality criteria covering currency of information, its reliability, user involvement in development, and accessibility." The Picker Institute was commissioned by the Department of Health in England to carry out a brief research study to inform the development of the scheme.

The study aimed to determine the current quality of health and social care information to enable an assessment of the costs and added value of accrediting information providers. We were asked to focus on four specific clinical information topics and to produce an estimate of the number and types of information providers offering information about specific diseases or conditions (COPD and arthritis), well being (healthy eating), and a topical public health issue (MMR); to obtain copies of relevant information materials and apply a defined set of criteria to determine their quality; and to make an assessment of the likely overall impact of making better information available to patients, carers, health and social care staff, and members of the public.

1.1 Overview of the study

There were four stages to the study:

I. A review of research evidence on patients' information needs and the likely impact and effectiveness of making high quality information materials more widely available and accessible.

II. A web search, an email survey of health information specialists, and a review of official statistics were conducted to produce an estimate of the number and type of providers offering patient information. Information specialists were also asked for their views on the proposed accreditation scheme.

III. A sub-set of 40 information materials identified in the search was evaluated using an evidence-based quality checklist. The clinical content of the materials was assessed with reference to an overview of systematic reviews and epidemiological studies.

IV. A telephone survey of representatives of the organisations that had developed the information materials was organised to obtain information on the development process. Interviewees were also asked for their views on the proposed accreditation scheme.

The methods and results of each of these four sub-studies are described in the following chapters.

1.2 Criteria for assessing the quality of patient information materials

Assessing the effectiveness of providing health information to patients and the public is not straightforward. Health information is required for a wide variety of purposes, including building knowledge and understanding of health conditions; helping people to decide when they need to seek specialist help; supporting choices in relation to treatment, management or social care options; identifying, choosing and accessing appropriate healthcare providers; and educating patients and the public about public health risks and about primary and secondary prevention. A broad term to describe all this is *health literacy*, which has been defined as *"the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the health care system, the market place and the political arena"* (Kickbusch 2005).

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Improving levels of health literacy should therefore be a central goal of public health, and the test against which any investment in health information should ideally be judged is the extent to which it improves health literacy. Unfortunately, baseline data on levels of health literacy do not exist for the UK because *health* literacy (as opposed to basic ability in reading and writing) has not been studied at a population level.

The Department of Health asked us to focus on “the extent to which the information leads to better decisions or reduces anxiety”. Patients with COPD or arthritis will face treatment and management decisions and will need practical advice on self-care, parents of young children must make decisions about MMR vaccination, and people concerned about weight gain must make appropriate dietary choices. Ideally, we would have wanted to study the effects of each of the selected materials to determine the extent to which it helped people make appropriate decisions. We reviewed the research evidence on the impact of health information more generally, but the limited time and resources available did not allow for a detailed assessment of the effectiveness of the specific materials under review. We had proposed carrying out focus groups with patients and members of the public to obtain their views on the quality of the information materials, together with independent reviews by clinical academics, but the Department of Health was unable to commission these components of the proposed study. Instead we used an ‘off-the-shelf’ quality checklist, suitably adapted, to assess the extent to which existing information materials comply with evidence-based criteria for the type of decision support that patients need.

There have been a number of initiatives designed to clarify users’ needs and improve the quality of health information, including the development of several quality checklists (Eysenbach et al 2002, Eysenbach & Kohler 2002, Pew Internet and American Life Project 2006). Principal among these are the King’s Fund guidelines (Coulter et al 1998), the DISCERN instrument (Charnock et al 1999), the BIOME guidelines promoted by Organising Medical Networked Information (OMNI) (Organising Medical Networked Information 2006), the Health on the Net Foundation’s principles (Health on the Net Foundation 2006), the European Commission’s quality criteria for health-related websites (European Commission 2006, Wilson 2002) and, most recently, the standards and criteria developed by the International Patient Decision Aid Standards (IPDAS) collaborators (IPDAS Collaboration 2005b).

It is helpful to think of assessment criteria in two categories: those that are aimed at assessing the content of specific information materials, and those that relate to the process of development and dissemination. The publishers of each of the six sets of guidelines had slightly different aims, but there is a reasonable degree of congruence in the topics covered (see tables 1 and 2).

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Table 1: Criteria for assessing the content of specific information materials

	King's Fund	DISCERN	OMNI / BIOME	Health on the Net	European Commission	IPDAS
Accuracy and reliability	✓	✓	✓			✓
Balance	✓	✓				✓
Clarity of aims and target audience	✓	✓	✓		✓	✓
Comprehensibility and readability	✓					✓
Coverage and comprehensiveness	✓	✓	✓			✓
Currency (i.e. up-to-date)	✓	✓	✓			✓
Links to further information sources	✓	✓	✓			✓
Privacy/confidentiality				✓		
Reference to sources / strength of evidence	✓	✓		✓		✓
Relevance to target group and ease of use	✓	✓	✓			✓
Style and attractiveness of presentation	✓		✓			✓
Support for shared decision-making	✓	✓				✓
Transparency of sources, authorship and credentials	✓	✓	✓	✓	✓	✓
Transparency of sponsorship	✓		✓	✓	✓	✓

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Table 2: Criteria for assessing the development and dissemination process

	King's Fund	DISCERN	OMNI / BIOME	Health on the Net	European Commission	IPDAS
Accessibility	✓		✓		✓	✓
Accountability and user feedback					✓	✓
Arrangements for updating	✓				✓	✓
Clarity of aims and target audience	✓	✓	✓		✓	✓
Consideration of minority group needs	✓					✓
Cost and feasibility of distribution	✓					✓
Honesty in editorial and advertising policy				✓	✓	
Methodology for assessing and applying evidence	✓		✓			✓
Peer review and/or evaluation by patients/professionals	✓					✓
Plan for application in clinical settings	✓			✓		✓
Responsible partnering and reliable links					✓	
User involvement in development	✓					✓

Of these sets of standards or guidelines, those from the King's Fund and the IPDAS collaboration have the advantage of being the most comprehensive, covering both content and development. Of these, the IPDAS standards are the most up-to-date, evidence-based (an extensive literature review was carried out by a large group of international experts) (IPDAS Collaboration 2005a), and they were developed following an extensive international consensus process involving a wide range of stakeholders. We therefore decided to apply these standards, adapting the checklist where necessary to accommodate the specific requirements of this study.

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2 What are the benefits of good quality health information?

Prior to the commencement of this study, the Picker Institute conducted an extensive literature search to identify and compile evidence on the effectiveness of patient information. The main findings of this review are summarised below, together with a summary of results from several other studies that looked at patients' information needs.

2.1 What information do patients want and where do they look for it?

Good quality information for patients about health problems can help:

- To prevent disease
- To promote self-care
- To inform treatment decisions
- To improve the effectiveness of clinical care.

A focus group study that asked patients to say what they wanted information for found that the following reasons were most commonly cited (Coulter et al 1998):

- To understand what is wrong
- To gain a realistic idea of prognosis
- To make the most of consultations
- To understand the processes and likely outcomes of possible tests and treatments
- To assist in self-care
- To learn about available services and sources of help
- To provide reassurance and help to cope
- To help others understand
- To legitimise help-seeking and concerns
- To identify further information and self-help groups
- To identify the 'best' healthcare providers.

For most patients the first and most trusted information source is their doctor, although many also seek out supplementary information from a variety of sources. A telephone survey carried out with a national random sample of the UK population in 2005 asked respondents (n=3,000) where they looked for health information: the majority (80%) said they were likely or very likely to seek out information to learn about how to cope with health problems (Ellins & Coulter 2005). Nearly three-quarters said they'd expect their doctor to provide it, but a wide variety of other sources were also mentioned (see table 3):

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Table 3: Sources of health information

Source	Percentage
Doctor	73%
Internet/website	30%
Leaflets or books	23%
Nurse/other health professional	22%
Family and friends	19%
Newspapers or magazines	18%
Pharmacist	6%
Patient organisations	4%
Television or radio	4%
Advertisements	1%
Other	12%

However, faith in doctors' expertise is beginning to be eroded. Younger patients see themselves as far more informed than the previous generation and younger middle-class people, in particular, no longer regard the medical profession as the fount of all knowledge (MORI 2001). Many are active information-seekers, not because they naturally distrust the doctor, but because they have a greater awareness of the variety of medical opinions and are used to seeking information from a variety of sources before making major decisions of any sort. There are some exceptions to this trend: for example, some patients with severe conditions may be fearful of finding additional sources of information in case it contains bad news (Leydon et al 2000).

Women tend to be more active information-seekers than men and people with chronic illnesses and parents with children at home often go to considerable lengths to obtain health information. Many people find that exchange of experiences with other patients or ex-patients is the most reassuring and efficient way to get information. The internet is increasingly used as a source of health information, particularly by younger and more educated people. People welcome the opportunity it gives for quick access to information from anywhere in the world, but many find the quantity of health websites overwhelming and finding reliable information takes considerable time and effort (Bessell et al 2002, Coulter & Magee 2003).

The extent to which people are motivated to understand their health problems is an even more important predictor of internet use than demographic factors (Mead et al 2003). People who believe that access to information will enable them to deal better with their health will go to considerable lengths to obtain relevant information and use is highest amongst those with internet access at home. The latest Social Trends report revealed that 56% of UK households have internet access and more than half of these are broadband connections (Office for National Statistics 2006). This gives a very large pool of people who are likely, at some time or another, to search the internet for health information.

2.2 How effective is patient information?

The scope of our review of the effectiveness of patient information was broad in terms of the types and topics of information covered, including general and personalised leaflets, alternative format resources (eg audio, video and interactive media), patient decision aids, and self-care and educational materials. Many different outcome measures have been used in evaluation studies to measure the effects of patient information. In this review, outcome data were selected and reported according to the following four categories:

- **patient' knowledge**: effect on patients' knowledge and information recall
- **patients' experience**: including patient satisfaction, quality of life and psychological wellbeing
- **service utilisation and costs**: including impact on doctor visits, hospital admissions and cost-effectiveness
- **health behaviour and status**: including effects on self-care behaviour, disease severity, symptom management and clinical outcomes.

Where possible we sought evidence from high quality systematic reviews, in particular those conducted by the Cochrane Collaboration, National Coordinating Centre for Health Technology Assessment (NCCHTA) and National Institute for Health and Clinical Excellence (NICE). In the absence of these, we drew on randomised controlled trials and other non-experimental studies.

Before considering the evidence on effectiveness, it is important to note that the impact of patient information crucially depends on the context and way in which it is used. Information is part of a broader process, and should supplement and reinforce professional advice rather than replace it (Garlick 2003). Indeed, there is a key role for health professionals in this process: to ensure that patients are able to access and understand resources, and to talk over the information and any decisions that may be made on the basis of it. Without this support from professionals, patients may feel confused by what they receive or face difficulties relating it to their own circumstances. Therefore, optimal strategies for the dissemination and implementation of patient information are essential. Moreover, where positive effects have not been found in studies evaluating patient information, this could equally reflect problems with context/delivery or with the actual content of the materials.

2.3 Impact on knowledge and recall

Patients often misunderstand or do not remember things that they are told during clinical consultations. Providing patients with information is intended to enhance their understanding of health and treatment issues and their retention of information over time. The extent to which patient information achieves these goals is an important question, and impact on knowledge and recall has been examined in the majority of evaluation studies.

Encouragingly, research has generally demonstrated the effectiveness of patient information in improving knowledge and recall (Coulter and Ellins 2006). This includes studies of written materials (McPherson et al 2001); audiotape, videotape and interactive media (Luck et al 1999, Murray et al 2005, Santo et al 2005, Scott et al 2001); and patient decision aids (Edwards et al 2000, Estabrooks et al 2001, O'Connor et al 2003). The additional value of providing written information was evaluated in a Cochrane systematic review, which identified trials that compared verbal information only with combined verbal and written information (Johnson et al 2003). This found that the combined method was significantly more effective at improving patients' knowledge and satisfaction. Fewer studies of personalised patient information have been conducted, but initial findings are promising. A study by Jones and colleagues compared general and personalised computer-based information for patients with cancer (Jones et al 1999). People offered personalised materials were more likely to use them, find them relevant, show them to others and feel that they had learnt something new. Information is also more effective either when

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used as an adjunct to the professional consultation or delivered as part of an educational intervention.

The information presented in decision aids focuses on treatment options and their possible outcomes, and is specifically intended to inform and support patients' involvement in clinical decision-making. There is strong evidence for the effectiveness of decision aids, which improve both patients' knowledge and their realistic expectations of the benefits and harms of treatment (O'Connor et al 2003). Impact appears to be greatest when risk information is presented in a way that is relevant to an individual patient or group of patients (Edwards et al 2000). While decision aids may make patients more aware of treatment uncertainties and risks, they are not associated with increased anxiety. However, anxiety may not be an appropriate measure of effectiveness, as raised levels of patient anxiety are associated with more effective decision strategies (Bekker et al 2003).

People with low health literacy often struggle to make sense of and use standard health information (Ad Hoc Committee on Health Literacy 1999), and could benefit from specifically designed low-literacy materials. The availability of such materials is particularly important given that low health literacy is more prevalent among health disadvantaged groups including the elderly, ethnic minorities and socially deprived (Institute of Medicine 2004). Most studies involving low-literacy groups have tested interventions that are designed to improve communication through the use of pictorial, videotape and interactive formats or simplified written materials. While improvements in knowledge have been shown, this has often occurred in all patients irrespective of their health literacy status or in all except those with the lowest literacy level (Berkman et al 2004, Eakin et al 2002, Moudgil et al 2000). However, there is evidence to suggest that disadvantaged groups derive greater benefits from computer-based health information systems, due to their particular style of use (Gustafson et al 2002). Other studies have found that the comprehension of health-related information by patients with low health literacy is substantially improved by the use of pictograms in addition to text (Berkman et al 2004, Mansoor & Dowse 2003).

2.4 Impact on patients' experience

A wide range of different outcomes fall into the category of patients' experience, many of which are strongly valued by patients themselves. These might cover patients' satisfaction, quality of life or psychological wellbeing, but can also include the interactive and communicative aspects of healthcare encounters. While studies of written information materials and decision aids have produced mixed results for patient satisfaction, findings for alternative format resources and low-literacy interventions are generally positive (Coulter and Ellins 2006). Patients consistently show strong preferences for health information that is delivered using audio, visual or interactive media (Institute of Medicine 2004, Nicholas et al 2004, Santo et al 2005). Among those with low health literacy, satisfaction is also improved by simplifying the language used in information resources (Holmes-Rovner et al 2005). While satisfaction with information received correlates with quality of life (Annunziata et al 1998), studies have not yet demonstrated direct effects of information on quality of life outcomes.

It might be expected that the proliferation of patient information will eventually change the dynamics of the professional-patient relationship. On this issue, some health professionals have raised concerns about the time involved in managing information enquiries, especially those generated by patients' use of the internet. However, there is some tentative evidence that internet information can positively influence the healthcare encounter, for example by encouraging

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patients to raise pertinent questions and concerns and feel more confident when communicating with their doctor (Eysenbach 2003). Additionally, decision aids have consistently been shown to improve patients' involvement in decision-making processes and the level of agreement between patients' values and treatments chosen.

Psychological factors (such as levels of depression or anxiety) are not necessarily appropriate outcomes for measuring effectiveness. Not all patients seeking information will have psychological problems, and interventions which include a counselling component may be more suitable for improving such difficulties than information per se. Nonetheless, trials have found that pre-operative or pre-screening information can reduce emotional distress (Howells et al 1999, Humphris et al 2001), and that decision aids and information leaflets can inform patients about treatment risks without increasing their anxiety (Garrud et al 2001, Whelan et al 2001). Computer-based systems which combine information delivery with online discussion groups significantly improve social support among people with chronic conditions. This finding is particularly important given that social networks are often disrupted by the onset of chronic illness, and that social support is known to reduce stress, improve coping skills and be generally beneficial for wellbeing in this group. Finally, research has found that a lack of appropriate information creates uncertainty for patients, and is itself a major source of worry and concern.

2.5 Impact on health service utilisation and costs

A key issue in the evaluation of healthcare interventions is whether, and to what extent, they affect patterns of health service utilisation and/or expenditure. There is less evidence on organisational outcomes than on those relating to knowledge/recall and the patients' experience, and more research in this area is needed. So far, the most promising studies have involved structured patient decision aids (Coulter and Ellins 2006). Despite fears that encouraging involvement in decisions will lead to an increase in demand for medical treatment, the opposite seems to be the case. When patients are provided with appropriate information and encouraged to express their preferences, they often choose less expensive options. For example, a systematic review by O'Connor and Stacey found eleven trials which focused on patients' decisions regarding elective surgery. A meta-analysis of these trials showed that uptake of surgery was reduced by 24%, in favour of more conservative options (O'Connor & Stacey 2005).

An earlier Cochrane review led by the same author found three studies which reported cost data, two of which found that decision aids using web-based technology were cost-neutral compared to usual care (O'Connor et al 2003). The remaining study was a large randomised trial of decision support for patients with menorrhagia carried out in the west of England (Kennedy et al 2002). The intervention comprised a booklet for patients (setting out the treatment options and outcomes) and a video; the trial involved two intervention groups, one of which additionally received nurse coaching to help clarify values and elicit preferences. There was a significant reduction in hysterectomy rates in the decision aid plus coaching group, which in turn led to lower service costs. Even taking into account the higher outlay costs, this combined intervention was found to be the least expensive overall (see table 4).

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Table 4: Cost-effectiveness of patient decision support for menorrhagia

Decision support for menorrhagia	Average cost per patient	Average quality adjusted life year
Standard care	£1810	1.572
Decision aid	£1333	1.567
Decision aid plus nurse coaching	£1030	1.582

Further indication of potential cost-effectiveness is provided by studies involving people facing screening decisions. Decision aids that provide individualised risk information generally increase uptake of screening (Briss et al 2004, Edwards et al 2003). However in the case of prostate cancer (PSA) screening, where there is controversy over the accuracy and value of testing, rates are appropriately reduced (Whelan et al 2001).

Few other studies have reported improvements in service outcomes, and it has been suggested that impact would be enhanced by delivering information as part of a combined intervention (Gibson et al 2002). The Jones and colleagues study cited above found printed information leaflets for cancer patients cost more than twice that of computer-based information (Jones et al 1999). The authors also noted that, if tailored information could be generated by an electronic version of the patients' medical record, there would be no additional cost over generalised materials. Compared to verbal information alone, combined verbal and written discharge information can significantly reduce the rates of return visits for emergency care (Johnson et al 2003).

2.6 Impact on health behaviour and health status

Often a central aim of patient information is to influence patients' health and self-care behaviours, and in doing so improve their health outcomes. Findings on the impact of general information leaflets and decision aids on health behaviours/status are mixed, with studies reporting both positive and neutral effects (Coulter and Ellins 2006). There is no evidence, however, of any negative impact on these outcomes. By contrast, there is good evidence for the benefits of computer-based health information systems (which combine information delivery with social support and/or decision-making tools). Murray and colleagues found seven trials of computer-based systems involving people with chronic conditions, all of which reported positive effects on self-care behaviours (Murray et al 2004). Benefits were also consistently reported for clinical outcomes, which were measured in ten trials. These 'information-plus' systems have also been shown to bring about positive behavioural change in populations that do not have a chronic condition (Wantland et al 2004).

Behavioural improvements have also been observed in studies involving people with low health literacy, although these have often evaluated multifaceted interventions of which patient information is only a part. For example, Moudgil and colleagues reported a significantly reduced number of asthma events or episodes following a package including health information, tailored self-management plans and an educational programme (Moudgil et al 2000). The participants were white and south Asian residents of economic deprived areas in Birmingham and materials were developed in appropriate ethnic dialects. However, only in the white group were clinical improvements reported. The authors speculate that a more culturally sensitive approach, directed towards health attitudes and beliefs as well as the clinical aspects of the condition, might have been more successful. Nonetheless, studies such as this suggest that patient information is a critical component of successful approaches to improving the wellbeing of patients who have health literacy difficulties.

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There are also some positive findings for information leaflets or manuals containing self-help guidance. When measured by reduction in cholesterol levels, information materials are an equally effective method of delivering dietary advice as specialist dieticians (Thompson et al 2003). They also cost considerably less; for example, one trial found that similar outcomes were produced by dietician advice costing $370 and self-help information costing $80. Self-help materials are also associated with an improvement in symptoms among those with anxiety or depression, and there is evidence that effects are sustained for up to three years (van Boeijen et al 2005). Improvements are greatest when patients are given guidance from a health professional in using the literature, compared to self-directed use.

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3 Who provides health information?

A multi-pronged approach was adopted to identify key sources of information written specifically for patients and the public on each of the following topics:

- chronic obstructive pulmonary disease (COPD)
- arthritis (rheumatoid arthritis and osteo-arthritis)
- healthy eating/obesity
- measles mumps and rubella (MMR) vaccination.

3.1 Internet search

A series of internet searches were carried out using the Google search engine to identify patient information available on, or via the Internet for each of these four indicator conditions. A number of different search terms were employed for each condition and ten Google pages were examined for each search term to identify providers.

Relevant websites were bookmarked and any suitable information leaflets were obtained or downloaded for later assessment.

3.2 Survey of information specialists

Since the Google searches could only identify information that is readily accessible on the internet, we also carried out an email survey of people with an interest in patient information asking them to help us locate additional information materials on the four topics. These contacts were also asked to give their views on the proposed accreditation scheme (see appendix 1).

This email request was sent to:

- subscribers to the Picker Institute's Good Practice database: 2,008 people
- members of the Patient Information Forum: approximately 150 people.

We received 104 replies to this request. The majority of respondents (n=72) were based in NHS or government organisations, with the remainder working in research/academia (12), the voluntary sector (10) or commercial companies (7). Three replies were received from individuals based outside the UK.

In response to our request for information materials, we were provided with details or samples of a wide range of resources across the four topic areas. Some of these materials (n=6) had been developed within NHS trusts and had not been identified by the Google search. Respondents also mentioned a variety of externally produced information resources used instead of, or in addition to, any in-house materials. Some information providers were mentioned by multiple respondents, and were therefore noted as a likely source of information for many patients. These were:

- British Lung Foundation (24 mentions)

- Arthritis Research Campaign (17 mentions)
- Department of Health (16 mentions)
- Arthritis Care (13 mentions)
- Patient UK (12 mentions)
- NHS Direct Online (11 mentions)
- British Heart Foundation (9 mentions)
- Boehringer Ingelheim (8 mentions)
- NHS Patient Information Bank (7 mentions).

In some cases, respondents specifically commented on the popularity of, or reliance on, materials from certain providers. For example, respondents commented that much of the information on COPD is produced by the pharmaceutical industry (and the company Boehringer Ingelheim in particular) or the British Lung Foundation. The charities Arthritis Care and Arthritis Research Campaign were mentioned as widely used producers of patient information on arthritis and related conditions. It also emerged that many patients are directed to centralised NHS resources (eg NHS Direct Online and the Patient Information Bank), as these are felt to be reliable and of good quality. Department of Health/NHS is also a key resource for patient information on MMR and healthy eating. General sources considered to be valuable included Patient UK, Best Treatments, the BBC and Prodigy.

3.3 Number of information materials and providers

These two methods identified a total of 285 patient information materials on COPD, arthritis, healthy eating and MMR provided by 237 organisations. These broke down as follows:

Table 5: Number of health information materials identified

	Google	*Survey*	*Total*
MMR	58	5	63
COPD	31	12	43
Healthy eating	99	27	126
Arthritis	43	10	53
Total	*231*	*54*	*285*

Of the total of 237 organisations, 87% (207) offered information on one topic only, while the remainder covered two, three or all four topics:

- 17 providers covered two topics
- 8 providers covered three topics
- 5 providers covered all four topics.

Information providers were classified according to whether they were not-for-profit voluntary sector, public sector, or commercial sector enterprises. The breakdown of the 237 organisations offering information on one or more of the clinical topics was as follows:

- 43% public (n=101)
- 30% commercial (n=72)
- 27% voluntary (n=64).

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3.4 Statistical review

Estimating the total number of providers of information relating to health and social care is a somewhat daunting task, given the potential range of topics and diversity of organisations. This is not the first time such an attempt has been made. A recent report to the Department of Health (MindCraft 2005) estimated that approximately 180,000 organisations were information providers. This estimate was based on the proportion of registered charities that cover the medical, health and sickness category (10 per cent) extrapolated to organisations in the wider economy.

We were concerned that this approach may have resulted in a significant overestimate. Given that the overriding aim of charities is to benefit the public, we would expect a high proportion of those focused on health and social care to be information providers, but not necessarily all of them. Furthermore it seemed likely that information provision was not restricted to this category of organisations, but the proportion offering patient or public information on health and social care in other organisational groupings was probably considerably smaller. Clearly, a more systematically derived estimate was needed and one that was sensitive to the potential diversity of information providers.

Our approach was also top down, but differed in that it made use of the UK Standard Industrial Classification (SIC). The SIC was first introduced in 1948 as a means of categorising UK businesses according to their primary economic activity. As all businesses are categorised, including charities and not for profit enterprises, the SIC becomes a powerful tool from which to draw a representative sample.

The SIC consists of 62 divisions (activities), one of which relates directly to health and social care (division 85). Whilst we would expect a reasonable proportion of these enterprises to be providers of health and social care information, any focus exclusively on this code risked underestimating the potential for organisations outside of health and social care to be health information providers. For example, it is not unreasonable to assume that some organisations in the agriculture and fishing divisions might provide information on healthy eating, whilst others in the retail trade division might use information to support the sale of health products.

Our approach was an inclusive one with the intention of sampling the entire spectrum of enterprises in the UK economy to give as complete a picture as possible. Our sample calculations were based on a conservative estimate - in terms of sample size – of the number of information providers. We started from the assumption that if the number of providers was as high as 15 per cent, then an achieved sample of 196 enterprises would be needed, assuming a 95 per cent confidence level with a margin of error of five per cent.[1]

The Office for National Statistics (ONS) provided us with population figures for all VAT registered and/or PAYE based enterprises across the SIC divisions. We used these data to draw a random sample stratified by the proportion of enterprises within each division. This stratification strategy ensured that within divisions enterprises would have an equal opportunity of being randomly selected. Furthermore, it ensured that those within more highly populated divisions would be disproportionately sampled compared to those divisions with very few enterprises. This approach ensured that our sample reflected the full profile of UK economic activity.

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[1] Whilst the margin of error is perhaps large in terms of the resulting number of enterprises, it was a necessary compromise for our sample for scale and manageability purposes. If we had reduced the margin of error to one per cent, for example, this would have entailed searching the websites of almost 5000 organisations, leading to a large number of follow-up phone calls.

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The FAME database was used as our sampling frame. FAME contains the operating details of all enterprises registered at Companies House, including primary SIC codes, website and contact details. Importantly, in addition to the private sector this database includes charities, not-for-profit organisations and those from the public sector. We examined the websites of each of the 196 enterprises in our sample to determine if they provided health or social care information. Where the website was unavailable or unclear, follow up phone calls were made to determine whether or not the organisation was a provider of health and social care information.

The final results of our review are shown in table 5. Of the 196 enterprises investigated, six were found to be providers of health and social care information. This represents three per cent of all organisations in the UK economy with a +/- five per cent margin of error. The latest data from the ONS showed that there were 2,007,570 enterprises in the UK in March 2005. Our finding of three percent translates to 61,456 current health and social care information providers. However, given the estimated margin of error, it is possible that this is as high as eight per cent, or 160,606 enterprises.

Table 6: Number of health information providers across the UK economy

SIC Description (Code)	*Number of Enterprises*	*Sample Enterprises*	*Information Providers*	*% of IPs within SIC Code(s)*
Wholesale trade (51)	111,155	11	1	9%
Retail trade (52)	201,435	20	1	5%
Education (80)	26,640	3	1	33%
Health & social care (85)	73,370	7	3	43%
All other 58 divisions	1,594,970	155	0	0%
Total	*2,007,570*	*196*	*6*	*3%*

The six health and social care information providers identified in our review were found across four SIC divisions. The percentage of enterprises that are information providers within these four areas are as follows: nine per cent of enterprises within wholesale trade, five per cent within retail trade, a third of those within education and 43 per cent of enterprises within health and social care.

In summary, it seems reasonable to conclude from this stratified random sample that three per cent of all UK enterprises are providers of health and social care information, giving a pool of approximately 60,000 organisations that might be interested in an accreditation scheme.

3.5 Gauging the potential level of interest in an accreditation scheme

As we have seen, our searches for providers of information on the four clinical topics yielded 237 organisations, the majority of which (87%) produced information on only one topic. It is quite difficult to assess what proportion of these 'single issue' organisations might want to seek accreditation. Our survey of providers (see chapters 5 and 6) found a high level of interest among the larger, single issue voluntary organisations and amongst those organisations where information provision was a core activity. There was less interest in securing accreditation amongst some organisations that provided information across multiple topics, for example NHS trusts, for whom information provision is a peripheral activity. Much will depend on the perceived costs and benefits to providers of the accreditation scheme (see chapter 6).

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4 How good is the information?

Having collected sufficient quantities of patient information materials to make an assessment of the range available on each of the four topics, we selected a sub-set in each category for further evaluation (see appendix 3). Not all of the materials highlighted by the internet searches and the survey of information specialists were designed to inform treatment decisions or public health choices, so selection criteria were applied to identify materials appropriate for assessment.

Materials chosen for assessment were those:

- Developed by UK-based organisations
- Written specifically for a lay audience
- Referring to at least one treatment option (in the case of COPD and arthritis)
- Offering practical advice (in the case of healthy eating and MMR).

Selection was designed to be purposive rather than comprehensive, so our final list of 40 materials was chosen to:

- Achieve a balance between types of information provider, including voluntary sector organisations, health authorities and trusts, commercial sources and professional organisations.
- Include both simple websites or leaflets and, if available, more complex information packages (ie including audio or video, or interactive computerised material, but excluding books).
- Identify at least ten materials on each topic for detailed review (ie a minimum of 40 materials in all)
- Include material from those providers that were mentioned by multiple respondents in the information specialists survey.

4.1 Assessing the content of the information materials

We identified relevant systematic reviews on COPD, arthritis, obesity and healthy eating, and MMR to enable the evaluation of the quality of the clinical information contained in the information materials. Searches were restricted to quality-assessed overviews of systematic reviews relying mainly on Clinical Evidence (BMJ 2006), supplemented by searches for relevant systematic reviews in the Cochrane Library, and NICE guidance and reviews.

The results of the searches were presented in a common format under the following headings: definitions and explanations of the condition, measures of severity, incidence and prevalence, survival/mortality, causative factors, methods of prevention, and “treatments likely to be beneficial” and “treatments possibly beneficial” using the classification adopted by Clinical Evidence. The reviews were carried out independently of the assessment of patient information materials, but an iterative process was adopted to ensure that the evidence provided met the needs of the reviewers.

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4.2 International Patient Decision Aids Standards (IPDAS)

As we explained in chapter 1, there have been a number of initiatives designed to clarify users' needs and improve the quality of health information, including the development of several quality checklists. Having reviewed these, the IPDAS standards were selected for use in this study.

4.3 Piloting and adaptation of the IPDAS checklist

Since the IPDAS criteria relate to information materials designed to support decisions about treatment or screening options, they required some adaptation to make them relevant to the broader range of information we were assessing. An initial round of piloting identified a number of important areas not covered by the IPDAS checklist, eg whether the piece of information included a clear statement of its aims. In addressing these omissions we drew on other quality criteria, in particular those included the DISCERN instrument (Charnock et al 1999). We also felt that the IPDAS checklist did not give sufficient weight to the important matter of accuracy and consequently added a section entitled 'contains accurate information'.

Following two further rounds of pilot testing some further minor adaptations to the IPDAS checklist were made and an appropriate scoring scheme was devised. In making revisions, efforts were made to retain all the evidence-based criteria whilst eliminating any areas of ambiguity. Six researchers tested the checklist and it was further refined until there was complete agreement on the meaning of each of the criteria and scoring was consistent. A few of the detailed criteria were felt to be too prescriptive for the purposes of this project and were therefore omitted. The final section is shown in table 7 overleaf.

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Table 7: Revised IPDAS checklist, section I (content)

I. Content: Does the information leaflet / website ……	
Start with a clear statement of aims?	**5 points**
Describes its purpose (e.g. to aid decision-making)	
Describes what it covers (to help the reader judge whether it's worth carrying on)	
Describes who it is for (i.e. which patient groups)	
Provide unbiased and detailed information about options?	**5 points**
Describes the health condition	
Describes the natural course without treatment	
Lists the treatment/management/lifestyle options	
Describes benefits of options	
Describes risks options (harms/side-effects/disadvantages)	
Describes uncertainty around the current evidence (i.e. what is not known)	
Describes procedures (ie treatments, targets, monitoring, behaviour change, etc.)	
Present probabilities of outcomes in an understandable way?	**5 points**
Uses event rates specifying the population and, if appropriate, time period	
Compares outcome probabilities using the same numerator/denominator, time period, scale (i.e. if numerators/denominators, time periods or scales are used, they need to be consistent)	
Uses visual diagrams and/or places probabilities in context of other familiar events	
Contain accurate information?	**5 points**
Clearly states the evidence sources used in compiling the information	
Information quoted is in line with the most up-to-date clinical evidence	
Where mentioned, prevalence estimates give an accurate impression of how common/rare the condition is	
Personal opinion and/or advertising are clearly distinguished from evidence-based information	
Help patients to make appropriate decisions	**5 points**
Acknowledges (explicitly or implicitly) that the patient has decisions to make	
Helps patients to imagine what it is like to live with the condition and/or treatment effects	
Asks patients to consider factors (e.g. priorities, motivations, treatment outcomes) affecting possible courses of action	
Suggests ways and/or provides tools to help patients make decisions	
Disclose conflicts of interest?	**5 points**
Includes authors' / developers' credentials or qualifications	
Reports source of funding to develop and distribute the patient decision aid	
Have a clear structure and layout?	**5 points**
Is consistent in design and layout throughout	
Includes aids to finding information (e.g. contents, index, site map, or search facility)	
Important points are emphasised through the use of summaries and/or bullet points	
Illustrates information with diagrams and/or pictures	
Where diagrams appear, they are labelled and relate to the subject matter	
Sections are clearly separated	
Help the reader judge its reliability	**5 points**
Reports date of publication	
Includes sources of further information	
Total score for content	**Out of 40**
BONUS POINT Includes information on social care issues	**Yes/No**

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4.4 Developing a scoring system

We based our scoring system on the approach developed and validated as part of the DISCERN project. This enabled us to award a score to each of the major sections within the checklist rather than a score for each sub-item, thus providing equal weighting to each major category. No attempts were made to vary the weights allocated to specific sections, since there was no valid way of determining the weights without further research and there was insufficient time available to carry out additional research.

Each of the eight sections was rated on a 5-point scale ranging from **no** (score of 1) to **yes** (score of 5). Assessors were asked to carefully consider the individual sub-criteria for each category as a guide before awarding a rating for each section.

- 5 was awarded if the material completely fulfilled the quality criteria
- Scores of 2,3 and 4 were awarded for materials which partially met the criteria with the actual score depending on the assessor's evaluation of the extent of any shortcomings
- 1 was awarded if the material did not meet the criteria in any way

With a total of eight sections each information material could therefore score a minimum of 8 points and a maximum of 40 overall.

Each of the information materials was assessed by two researchers working independently. In the event of any significant discrepancies (a difference of more than 5 points), a third researcher was asked to produce an independent rating to resolve the issue.

We wanted to further evaluate the usefulness of the IPDAS checklist by comparing scores against our own impressionistic mark for quality, so assessors were asked to note any comments and provide an overall mark for each material using the same 5-point scale. Assessors' comments have been used to illustrate some of the points in this chapter. Any materials mentioning social care issues were also noted.

4.5 Assessment of individual information materials

Scores achieved on section 1 of the IPDAS checklist are given in tables 8-11 below.

Table 8: Information on COPD

Provider	Name	Resource type	Mean score/40
British Lung Foundation	Living with COPD	Leaflet	**19.0**
Boehringer Ingelheim	Living with COPD	Leaflet	**31.0**
Chest, Heart and Stroke Scotland	Living with COPD	Leaflet	**26.5**
Prodigy	COPD: patient information leaflet	Website	**22.7**
South Warwickshire PCT/South Warwickshire General Hospitals NHS Trust	Pulmonary Rehabilitation Book	Leaflet	**24.0**
Department of Respiratory Medicine,	COPD	Leaflet	**20.0**

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New Cross Hospital, Wolverhampton			
York Hospitals NHS Trust	Living with COPD: information for patients	Leaflet	25.5
North Tees and Hartlepool NHS Trust	COPD: information for patients	Leaflet	23.3
Channel 4	Chronic lung disease	Website	17.0
BUPA	Chronic bronchitis and emphysema	Website	25.5

Table 9: Information on arthritis

Provider	**Name**	**Resource type**	**Mean score/40**
Arthritis Care	Living with osteoarthritis	Leaflet	28.5
Arthritis Research Campaign	Introducing arthritis	Leaflet	27.5
Nottingham City Hospital	A patient's guide to shoulder joint replacement	Leaflet	34.5
EIDO	Total hip replacement	Leaflet	30.5
BBC	The arthritis guide	Website	33.5
NHS Direct Online	Arthritis (Health Encyclopaedia)	Website	26.0
Bradford Teaching Hospital	Joint Action: information for patients	Leaflet	30.5
Home Health UK	Rheumatoid Arthritis	Website	18.0
AXA PPP Healthcare	Rheumatoid Arthritis	Website	24.5
National Aklylosing Spondylitis Society	Questions you may have	Website	29.5

Table 10: Information on healthy eating

Provider	**Name**	**Resource type**	**Mean score/40**
Food Standards Agency	Obesity (Eat Well, Be Well)	Website	16.0
British Heart Foundation	So you want to lose weight…for good	Leaflet	27.0
University Hospitals Coventry and Warwickshire NHS Trust	Weight loss, food facts and tips	Leaflet	20.5
National Obesity Forum	The public	Website	25.0
Best Treatments	Obesity	Website	33.0
Ipswich Hospital Trust	Want to tackle your weight/Want to lose weight	Leaflets	23.0
NICE	Guidance on the use of orlistat for the treatment of obesity: information for patients	Leaflet	26.0
British Dietetic Association	Weight Wise	Website	24.5
Net Doctor	Obesity	Website	17.5
Weight Concern	Losing Weight	Website	21.5

Table 11: Information on MMR vaccination

Provider	Name	Resource	Mean score/40
Department of Health	MMR Information Pack	Leaflet	37.0
MedInfo	MMR Vaccination	Website	28.5
DIPEx	Immunisation: making the decision	Website and multimedia	35.5
Treatment Notes	Should children have MMR?	Leaflet	30.5
Health Education Board for Scotland (now NHS Health Scotland)	MMR Discussion Pack	Leaflet	38.0
Bandolier	MMR Vaccination	Website	26.0
Babyworld	Explaining MMR	Website	23.0
Science Museum	The MMR Files	Website	30.5
Van UK – Vaccine Information Service	MMR Factsheet	Website	14.0
Medic8 Family Health Guide	MMR Vaccine: a patients guide	Website	16.5

It is important to note that in the case of websites, assessors did not examine the information material relating to a specific condition in isolation. The provider's entire website was checked to see if criteria were met (e.g. evidence sources, authorship etc). On the other hand, leaflets were assessed in isolation. This is an important issue which is discussed later in this report.

The mean score for the 40 materials assessed was 25.69, with 11 out of the 40 materials scoring means higher than 30.

On the whole there was a high level of agreement between assessors with the majority of materials achieving a similar score (any difference was less than 5 points). There were no significant differences between the mean scores awarded by individual assessors for each topic or within individual section scores indicating a highly consistent level of scoring. Only three materials out of 40 required a third assessment. All three of these materials related to COPD.

Only four of the information materials mentioned social care issues.

The length of time taken to assess the material proved highly variable and was dependent on both the medium and volume of the item. Assessors felt that the evaluation of websites was generally more arduous than paper-based material. Websites tended to take longer to assess and often proved more difficult to navigate to find all of the required information. Relevant information was not always readily available on the specific web page(s) under consideration, but could be found elsewhere on the website. In some cases, the layout of the web pages was not arranged in a user-friendly fashion, making the task even more difficult.

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4.6 Scores by topic

Table 12: IPDAS scores by topic

Topic/condition	Lowest score/40	Highest score/40	Mean score/40	Mean subjective assessment/5
COPD	17	31	23.43	2.96
Arthritis	18	35	28.30	3.80
Healthy Eating	16	33	23.40	2.95
MMR	14	38	27.95	3.40

These scores illustrate the wide range in quality of the information materials selected for assessment, with scores ranging from 14 to 38. It is worth remembering, however, that materials were pre-selected for this exercise and a completely random sample of all information materials might have demonstrated an even wider range of scores.

Interestingly, the range of scores awarded was similar for each of the conditions and there was no statistical difference between the mean scores in each of the topic areas. Information on Arthritis and MMR generally scored more highly than the materials relating to COPD and Healthy Eating, but this difference was not statistically significant. We cannot reliably conclude, therefore, that information available on one condition is any better or worse than the information available on another.

There was a positive correlation (0.89) between the cumulative score (ie how well the material met the IPDAS criteria) and the overall impressionistic mark awarded by assessors, indicating a high level of agreement between the subjective assessments and the IPDAS scores.

4.7 Scores by provider type

The range of scores given to the assessed materials was similar for all provider types with no significant differences between the mean scores awarded.

Table 13: IPDAS scores by provider type

Provider type	Lowest Score/40	Highest score/40	Mean score/40
Public	16	38	26.21
Commercial	17	34	25.04
Voluntary	14	36	25.62

4.8 Scores by section

Scores attained in the section relating to the **presentation of the probabilities of treatment outcomes** were significantly lower than the mean scores for every other section. Those relating to **accurate information** scored significantly lower than all the other sections apart from the **disclosure of conflicts of interest** and **probabilities of treatment outcomes.**

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Table 14: Ranked mean section scores

Section	Mean Score/5
Clear structure and layout	3.66
Clear statement of aims	3.61
Helps to judge reliability	3.52
Information about options	3.51
Helps patients to make appropriate decisions	3.40
Disclosure of conflicts of interest	3.07
Accurate Information	2.84
Probabilities of treatment outcomes	2.07

On the whole, many information materials tended not to focus on the **probabilities of treatment outcomes.** A high proportion failed to disclose their evidence sources and this often affected their score in the **accurate information** section. **Uncertainties relating to the clinical evidence** were hardly ever mentioned. Interestingly, the MMR materials scored more highly in these sections when compared with the others. This could be due to a stronger consensus on the evidence base in this instance and also because the options are quite limited – parents either choose to vaccinate their child or they don't. It may also be easier to present the outcomes of vaccination in terms of probabilities.

Some information materials tended to focus on only one or two treatment options and a significant number failed to mention any risks or side effects associated with these choices. Many of those that did mention the disadvantages of options provided little detail, and in several cases they started from the assumption that the decision had already been taken.

Table 15: Scores by topic and section

	Mean score per section/5							
Clinical topic	1 Clear statement of aims	2 Information about options	3 Probabilities of treatment outcomes	4 Accurate Information	5 Helps patients to make appropriate decisions	6 Disclosure of conflicts of interest	7 Clear structure and layout	8 Helps to judge reliability
COPD	3.48	3.26	1.35	2.22	2.96	2.48	3.91	3.78
Arthritis	3.90	3.65	2.10	3.40	3.75	3.55	4.10	3.85
Healthy eating	3.30	3.30	1.60	2.30	3.60	2.90	3.30	3.10
MMR	3.80	3.85	3.35	3.55	3.35	3.45	3.30	3.30
Total	**3.61**	**3.51**	**2.07**	**2.84**	**3.40**	**3.07**	**3.66**	**3.52**

Sections concerning **clear structure and layout**, **clear statement of aims**, **helps to judge reliability** and **information about options** tended to achieve higher mean scores. This could be because the criteria within these sections are relatively easy to meet, e.g. describing the purpose of the material and the intended audience, describing the condition and the options available, including the date and providing sources of further information. Assessors also reported that these sections were much easier to score.

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4.9 Paper versus Web information

The mean score (out of 40) awarded to paper-based information was **27.33**, significantly higher than the mean score of **24.16** given to web-based information.

Table 16: Scores by media type

Media type	Mean score/40
Paper	27.33
Web	24.16

Paper-based information tended to score better in the sections relating to **a clear structure and layout** and a **clear statement of aims.** Generally, assessors felt these domains were much easier to score and it was more straightforward to assess these criteria in paper-based information. Finding a clear statement of aims was often more difficult when looking at a website. Assessors felt that if they had trouble finding this information when they were specifically looking for it, then it was unlikely that many ordinary readers would come across it.

Table 17: Scores by media type for each section

Media type	Mean score per section/5							
	1 Clear statement of aims	2 Information about options	3 Probabilities of treatment outcomes	4 Accurate Information	5 Helps patients to make appropriate decisions	6 Disclosure of conflicts of interest	7 Clear structure and layout	8 Helps to judge reliability
Paper	4.08	3.58	1.98	2.80	3.63	3.25	4.13	3.90
Web	3.19	3.44	2.16	2.88	3.19	2.91	3.23	3.16

We were concerned that comparing an individual leaflet against an entire website would potentially bias the assessment towards the latter type of information. It is interesting, therefore, that the overall scores were higher for paper-based than electronic materials (a statistically significant difference). Nonetheless, there were certain instances where we felt that our choice of a single leaflet had potentially disadvantaged an organisation. Specifically, one leaflet we had assessed was intended as background information covering issues at a general rather than detailed level. However, we were aware that other materials produced by the same provider (which were intended as the next stage reading) developed key issues quite comprehensively.

> *'A simple overview…clear and easy to understand. However the info on treatment options is quite limited - no real facts about treatment benefits and nothing about risks/side-effects. But it is referenced well and includes further sources of information.'*

Any potential accrediting body would need to ensure parity between providers by discussing assessment material with them on a 'case by case' basis. For example some providers could be assessed on the content of their website whilst others might submit a collection of leaflets or materials.

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4.10 Other issues to consider

Information that does not focus on decision making

The assessment of these information materials highlighted an abundance of information that does not recognise or support patients' decision making role. A lot of material we looked at started from the assumption that treatment or management decisions had already been made. Such information may have its uses, but it is unlikely to meet all of the IPDAS criteria.

> *'Good info for this one procedure, but not enough detail on other options'*

Such information was often clear, detailed and well written for a patient audience, but it did not go into detail about other treatment choices or include aids to decision making.

> *'Really good summary of main issues, positively written, easy to understand and options to pursue. Info accurate but not much detail - is it needed for a general self help leaflet?'*
>
> *'Nothing on effects of obesity on health, but does not set out to do that'*
>
> *'A good, clear, concise leaflet. Lots of advice on pre and post surgery. No real decision options as assumes decision has been made – I don't think it should suffer for this'*

Information that scores well but requires improvement

Some materials scored very well against the IPDAS criteria and 'ticked all the boxes', but assessors felt they would have limited use for anyone who did not have the very highest levels of health literacy.

> *'Detailed but some info very text heavy! How many patients would understand references and where to look them up?'*
>
> *'Good info but a real academic focus'*

Equality of assessment

In nearly all cases assessors instinctively agreed whether the information was good or bad and in the majority of cases awarded a similar impressionistic score to that obtained using the IPDAS checklist. Any differences were almost entirely based on personal interpretation of how well the material met the IPDAS criteria.

Assessors found that some sections of the checklist were much easier to mark than others. For example, the date of publication, links to further information and details of authorship are relatively simple things for providers to implement, and they can also be objectively marked. Beyond this there is a greater likelihood that personal opinions will differ leading to greater variation in the scores. Finding a set of criteria which covers all types of patient information and where the options leave no room for any personal differences will not be easy. Any potential assessors would need rigorous training and any process would need to be extensively piloted to help ensure a consistency of approach when evaluating materials.

It is worth noting that despite the high level of consistency of marking throughout this exercise, assessors would only have to differ by one point in each section to produce an overall difference of eight points. If three independent assessors were to mark each material instead of two, this would help to ensure an even more consistently fair scoring system.

4.11 Use of clinical evidence to judge accuracy

In order to be able to accredit information materials on all conditions and health problems, a firm grasp of the clinical evidence will be necessary. Developing from scratch an up-to-date database of all relevant clinical information on all conditions and their treatment options would be a massive undertaking. Cases where the evidence base is thin or disputed could also prove problematic. It will be important to encourage information providers to be more explicit about areas of scientific debate and uncertainty, which are much more common than is often supposed. Assessors would have to be extremely well briefed to ensure they have a sound understanding of the research evidence. If the accreditation scheme goes ahead, it would be advisable to link it to an agency that is already involved in producing reliable reviews of clinical evidence.

A large proportion of the assessed materials did not discuss treatment options and probabilities in any depth. Again this may be because those writing the materials assume that patients don't want or need the detail, or because they start from the assumption that patients are not, or should not, be involved in treatment decisions. Basic descriptive information is still of relevance to many patients, but a strategy to improve health information quality should be ready to challenge such paternalistic assumptions. This should involve reminding information providers that many patients do expect to be actively involved in the decisions that affect them and they need sufficiently detailed information to allow them to do so.

> *'This is a good overview - lots of info and resources for further exploration. No real hard facts and figures but easy to understand and plenty of food for thought. Acknowledged patient as decision maker'*
>
> *'Although it ticked a lot of boxes, it lacked any detailed information'*
>
> *Not a huge amount of detail but think it does a good job and acknowledges options although no means of evaluating these'*

The evidence base for self-help strategies is often unclear but this sort of information could still be of practical use to many and its value should not be underestimated.

> *'Very good on lifestyle choices especially self-help and self-management, but poor on medication options.'*

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4.12 What worked well?

Assessors commented that there can never be a ‘one size fits all’ approach to patient information. They felt that the best information materials they evaluated were those that allowed access to different levels of information depending on your personal situation and individual requirements.

> *‘Very thorough and comprehensive with different levels of detail depending on the reader's need for information.’*
>
> *‘Excellent! Acknowledges parent as decision maker. Gives clear info and then provides additional information if required’*

There were also concerns that the production of creative information could be stifled by rigid guidance. Any future accreditation scheme would need to ensure a flexibility of approach which does not dampen the enthusiasm of the information providers and also meets the diverse needs and abilities of patients.

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5 How do providers develop patient information materials?

5.1 IPDAS criteria for assessing the quality of the information development process

The Department of Health's proposed health information accreditation scheme will principally accredit provider organisations, rather than individual pieces (or suites) of information. To achieve this, organisations will have to demonstrate that their information development process meets certain quality standards. The IPDAS checklist, which was used by the Picker Institute to assess health information quality, contains a set of criteria relating to the development process which could be employed for this purpose.

As originally developed, the relevant IPDAS criteria were:

- Uses a systematic development process
- Uses up-to-date scientific evidence
- Uses plain language.

A number of changes were made to these criteria to both refine and extend them. The plain language section was broadened to include other important usability issues. Specifically, a sub-item regarding field-testing draft materials with diverse patient groups and a bonus point for the production of translated information for non-English speakers were added. Equally important to the way in which materials are developed is the process by which they are distributed and publicised to patients and health professionals.[2] A comprehensive dissemination process increases the likelihood that information materials get to the right patients and are used to best effect. These issues were addressed in a new final section of the checklist (see table 18).

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[2] Although the term 'patients' has been used to describe the group for which health information is intended and used, we recognise that in practice organisations are developing information for many others including carers, parents and consumers.

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Table 18: Revised IPDAS checklist, section II (development process)

II. Development process: Do the information providers…..	
Use a systematic development process?	**10 points**
Finds out what information users (e.g. patients, carers, professionals) need to discuss options or decide on courses of action	
Involves users throughout the development process (e.g. assessing information needs, selecting topics)	
Has materials field tested by patients/carers not involved in development	
Has materials peer reviewed by patients/carers not involved in development	
Has materials reviewed by professional experts not involved in development	
If necessary, revise materials based on field testing and/or peer review	
Use up to date scientific evidence?	**10 points**
Reviews the clinical research evidence and use systematic reviews where available	
Has a procedure for regularly revising and updating information	
Address usability issues?	**5 points**
Written at a level that can be understood by the majority of patients in the target group (e.g. tested using SMOG/Fry, received Crystal Mark or produced a glossary)	
Provides additional ways to help patients understand the information other than reading (e.g. audio, video)	
Field testing involves groups of patients with different needs and abilities	
Have a dissemination plan?	**5 points**
Plan for how users will access the information	
Plan for how clinicians will be informed about it	
Plan for integrating it into clinical care	
Total score for development	**Out of 30**
BONUS POINT Produces translated materials in non-English languages	**Yes/No**

A sample of information materials produced by 40 UK organisations was chosen for detailed content assessment (see chapter 4). Between April 10 and April 17 2006 these same organisations were invited to participate in a telephone interview. The purpose of the interview was three fold:

- To collect background information on the provider: for example, their yearly expenditure on health information development; the number of people annually accessing their materials; and whether they have guidelines for producing health information
- To discuss the process of information development in their organisation, in order to complete the IPDAS assessment
- To elicit providers' views on the proposed accreditation scheme: including the organisation's likelihood of applying, their views on the quality criteria (IPDAS sections 1 and 2) and what areas they would need to improve in order to meet standards for accreditation.

Of the 40 organisations contacted, interviews were completed with a total of 31. Four organisations declined to participate, and persistent efforts to speak with individuals at the remaining five were unsuccessful. Of those nine organisations with whom we were unable to complete interviews, the majority were commercial enterprises. This should not be taken as an indication of reluctance in this sector as a whole, as some commercial organisations were very enthusiastic about participating.

Interviewees were told that their remarks might be quoted, but on a non-attributable basis. While we made our best efforts to talk to the person who was most closely involved in the information development process, this was not always possible. For example, many organisations commission external authors (eg expert clinicians, specialist medical writers or journalists) to research and

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write their patient information materials. These interviewees were often unable to give precise details on issues such as how clinical evidence is identified, assessed and used. As we discuss below, this in itself is an important finding, as it suggests that organisations that commission writers are not requiring them to follow a set of standard procedures. In larger organisations, different aspects of the development process may be overseen by different individuals or departments. Hence one person was not always able to give a complete account of how materials are produced within their organisation. This was further complicated in the case of NHS Trusts, where processes can vary from department to department, ward to ward or even clinician to clinician. Given this, we opted to speak to someone who would be able to give an overview of the Trusts' practice; in most cases, this was a representative from the patient advice and liaison service, a patient and public involvement manager or patient information specialist.

For an IPDAS assessment to be completed, the interviewee had to provide a detailed account of the information development process within their organisation. As the purpose of the interview was to conduct background research, rather than a formal evaluation, we were lenient in the level of detail required for scoring. However, in three cases, we were unable to assess the organisation against the IPDAS criteria, but valuable comments made during these interviews have been reported where relevant.

5.2 The information provider organisations

The 31 provider organisations (POs) we spoke to varied considerably in their size, purpose and in the scope of the information they provide. In terms of size, they ranged from small organisations run by a single person, through medium sized commercial enterprises, to large NHS Trusts. The majority produce information on a number of different issues, either across a range of the health topics or within a specific condition area. The POs were categorised as either commercial (n=7), public (n=12) or not-for-profit (n=12). These broad categories contain an assortment of different organisations; commercial organisations were defined as those who sell or make a profit from their information materials, or whose income is principally derived from advertising or charging for other products/services. 'Public' POs include NHS Trusts, centrally funded services and public bodies. Within the 'not-for-profit' category are charitable and voluntary associations, professional societies and other providers who operate on a non-for-profit basis. Given this variety, it is likely that some POs will have more in common with counterparts in other sectors than other organisations within their own sector. Thus caution should be applied in making generalisations by 'provider type'.

POs were asked a number of background questions, including their annual spend on developing and disseminating patient information. Many organisations were unable or unwilling to provide this data, with some (including an NHS-funded PO) commenting that these could not be shared for reasons of commercial confidentiality. Additionally, almost all the patient groups were willing to disclose, but could do so for expenditure on general educational activities, of which information development is only one part. Others were able to give precise details of their printing bill, but noted that this was not the same as overall development costs which would also need to take into account staff salaries, technical support and related activities (eg user testing, honoraria). Conversely, one large commercial PO reported spending approximately half a million pounds each year on patient information, but this did not include their printing costs.

The estimates we received varied substantially: from a low of £2,000 to a high of £5-6 million. To an extent, these figures will reflect the scope of the population that is being targeted by the organisation's materials: POs producing information for a relatively small or discrete patient group

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are likely to have lower development costs, compared to those covering a major disease area or broad range of health topics. Nonetheless, as expected, there was a relationship between the cost and quality of the development process. To illustrate, two POs that spent approximately £2,000 and £6,000 each year achieved low IPDAS scores of 10 and 9 respectively. Conversely, another PO that reported costs of around £1 million scored 28 overall (out of a maximum possible score of 30). This should not be taken to suggest that high quality development processes are the preserve of those spending millions of pounds, as equally good scores were reached by POs spending far less than this. However, it is clear that some aspects of information development which are rewarded in the IPDAS assessment are costly. For example, extensive user-testing conducted by one PO cost anywhere between £1,600 and £4,000 for each new piece of information. The same organisation usually asks up to 100 individuals to review their draft materials, each paid £20 per reading. Expenditure on printing at a major not-for-profit PO was £260,000 annually, and another spent £12,000 setting up their website (which cost an additional £200 each month to maintain).

One PO we were contacted by independently of the survey was able to give a detailed cost breakdown of their development process. All their materials are tested in one-to-one interviews with user groups before being printed. They are then vetted by relevant specialists and reviewed by an expert panel of health professionals. They are then evaluated by subscribers and redrafted on the basis of feedback received. The approximate costs for an average print run of around 150,000 to 200,000 are as follows:

- User testing = £3,000 - £4,000
- Printing = £15,000 - £20,000
- Design = £2,000 - £3,000
- Media work = £4,000
- Consultancy = £2,000 - £3,000
- Translation into nine languages = £2,000 - £3,000.

Where possible, POs also provided details of how many patients were using their information each year. As with the above issue, it was difficult for organisations to give precise figures. Some record the number of visits to their website, but this would include visits for all purposes (including accidental hits) not just to access health information. Reports on website activity included: 15,000 hits per day (small not-for-profit PO); 1,000 hits per week (medium not-for-profit PO); 40,000-50,000 per week (large not-for-profit PO); 5 million per year (medium commercial PO); 550,000 per year (large not-for-profit PO); 13.5 million per year (large public PO). Patients' use of information also cannot easily be calculated by the number of printed materials that are annually distributed, as POs cautioned. Leaflets may not be handed out, be handed out in error (and then discarded), or photocopied for use with multiple individuals. Some people will also receive more than one leaflet from the same organisation. Leaflet distribution rates included: 8,000 per year (small not-for-profit PO); 250,000 per year (medium not-for-profit PO); and 4.5 million per year (large not-for-profit PO).

In later discussion, POs were asked whether they thought they could reach a wider audience if they received accreditation for their patient information. A number of organisations were sceptical about whether accreditation would appreciably alter people's information-seeking behaviour, given that some patients are known to privilege information that fits their perspective or chosen course of action over sources which guarantee impartiality or are most evidence-based. It was also felt that patients would continue to explore a range of information, rather than being limited to those materials which carry an official stamp of approval. But the majority of POs expressed the opposite opinion: that growing awareness of the scheme would lead to increasing numbers of people seeking out information from quality assured sources. However, none of the interviewees was able to forecast the precise effects of accreditation by estimating the likely impact on usage of their materials. Indeed, this would be very difficult for POs to do, as various factors beyond the organisation's control will significantly shape the impact of an accreditation scheme. Outlined in detail below, these include whether awareness of the scheme is well established among the general public through promotional and marketing activities, and the extent which people know and trust the accrediting body.

5.3 Information development

Organisations were asked questions about various aspects of the information development process in order to complete the IPDAS assessment. A total of 30 marks could be achieved: 10 for section a. (systematic development process); 10 for section b. (up-to-date scientific evidence); 5 for section c. (usability issues); and 5 for section d. (dissemination plan). IPDAS was scored using a rating scale approach: if the criteria were not met in any way a score of 1 was given; if they were partially met a score of between 2-4 or 2-9 was given; and if they were fully met a score of 5 or 10 was given. In addition, a bonus point was awarded if the organisation produced translated materials in non-English languages.

The results of this assessment are shown in table 19. Three of the 31 organisations with whom we were able to arrange interviews were unable to provide sufficient detail to enable a quantitative assessment of their procedures, so results are presented for 28 only.

These results should be treated with caution for a number of reasons. First, in several cases the interviewee was not specifically responsible for developing the particular leaflet or website that we had selected for assessment. This was often the case in relation to NHS Trusts: our researchers were sometimes unable to speak to the actual individual involved so instead they talked to PALS staff or patient information specialists about general information development practices within the organisation. In other cases, we felt the providers were giving an unreliably positive description of their procedures. For the purposes of a formal accreditation process, we believe providers should be asked to submit a written description of their procedures and supply supporting evidence (eg instructions to authors). Because of these caveats and because some of our informants asked for anonymity, we have not identified the organisations assessed here.

From the overall scores, it was clear that organisations differed substantially in their processes for developing and disseminating health information. Scores varied from a low of seven to a high of 28, with an average of 19.75. Eleven organisations scored below the average, but three were only marginally lower with scores of 19. A key issue is whether certain factors account for the variation seen in the quality of the development process. Scores were not strongly patterned according to provider type (ie voluntary, commercial or public), but size of organisation was important. Generally, lower overall scores were more prevalent among the smaller organisations, and highest ones among the larger providers. This finding is unsurprising, given that larger providers are likely to have greater resources to devote to the production of health information. As expected, scores were also higher for organisations whose sole purpose is the production of information or for whom information provision is a major area of work, and lower where it is a supplementary or peripheral activity.

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Table 19: Scores achieved on section II of the IPDAS checklist

Type	Overall score (max 30)	Systematic development process (max 10)	Up-to-date clinical evidence (max 10)	Usability issues (max 5)	Dissemination plan (max 5)	Non-English languages
Public	28	9	10	5	4	Y
Public	28	10	10	5	3	Y
Commercial	27	10	10	2	5	N
Public	26	8	10	5	3	Y
Commercial	26	10	10	2	4	N
Voluntary	25	10	8	3	4	Y
Voluntary	24	8	8	4	4	Y
Public	24	8	10	3	3	N
Voluntary	24	8	8	5	3	N
Public	23	7	10	3	3	N
Commercial	22	8	8	2	4	N
Public	22	10	5	5	2	Y
Public	22	8	6	5	2	Y
Commercial	22	5	10	5	2	Y
Voluntary	21	8	7	3	3	Y
Voluntary	20	8	5	3	4	Y
Voluntary	20	7	7	3	3	N
Voluntary	19	5	10	1	3	N
Public	19	8	5	5	1	Y
Commercial	19	3	10	2	4	N
Voluntary	15	3	10	1	1	N
Voluntary	15	3	8	2	2	Y
Public	14	5	5	3	1	Y
Commercial	12	2	8	1	1	N
Voluntary	10	2	5	1	2	N
Commercial	10	3	5	1	1	N
Voluntary	9	2	1	2	4	N
Public	7	1	3	2	1	Y

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5.4 Uses a systematic development process

The extent to which users are involved in the information development is addressed in section a. of the IPDAS checklist. Such involvement is essential to ensure the information meets the needs and interests of those who will be using it, and this cannot be readily assumed. The term 'users' includes the patients, carers and consumers for whom information is intended, and the health professionals who give out written materials to these groups. POs widely acknowledged the importance of involving users in the development process, and many were keen to emphasise the various ways in which they were achieving this. However, we found significant variation among organisations in the type, level and impact of user involvement in practice. Moreover, in some instances, POs appeared to be overestimating their level of user involvement.

Almost all POs attempted to consult and/or involve users, although for a small number this was limited to showing drafts to a colleague, friend or family member. Professionals were often involved in writing materials and, along with patients, in reviewing them at draft stage. However, responses indicated that information was more likely to be sent to expert than lay reviewers, and there was an implicit assumption among some that having materials checked for clinical accuracy was more important than establishing their acceptability to patients. A wide range of practices were described as 'clinical reviewing': from showing drafts to an individual doctor (or couple of doctors), through approval by a clinical panel, to multi-stage reviewing processes involving a range of different participants. One interviewee, for example, described a sign-off procedure in which the draft materials and the supporting clinical evidence were extensively circulated around members of the organisation for review. A small number of POs described rigorous user-testing processes in which patients were asked, for example, to assess the readability of materials or comment on how well information fulfilled its intended purpose. One commented that such user-testing was not only expensive but also time-consuming, especially where this led to recommendations for major revisions/changes (which may also necessitate another round of user-testing to approve the new draft).

POs were also asked how they chose the topics and issues for new pieces of information, and we were particularly interested in the extent to which this process was user-driven. Some made strenuous efforts to ensure that new materials were produced in accordance with patients' needs. For example, one not-for-profit PO identified topics by consulting a variety of stakeholders; by contacting local branches of their support groups; and through a suggestions box on their information order form. They also, along with many other POs, reported that information was developed (or existing materials updated) in response to major developments such as a new service, treatment or set of guidelines, or a change in practice. Another PO conducted a bi-annual survey of their target audience, to gauge attitudes, knowledge and understanding of the issues. However, many other POs either chose the topics themselves or through consultation with health professionals. While this is not problematic per se, research in this area has shown that there can be significant disparities between expert views of what information patients want and need, and patients' own views. Within this criterion, we felt that incorporating patient preferences at the very start of the development process was the area that needed most attention.

5.5 Uses up-to-date scientific evidence

As with user involvement, almost all POs talked about the importance of producing evidence-based patient resources. Indeed, when asked to comment on the proposed criteria for assessing information materials (IPDAS section 1) there was strong approval of the item 'contains accurate information'. In marking this section, 17 organisations were given scores of eight or above (out of a possible ten), and only two achieved less than five. This is in stark contrast to the findings from our independent review of the information materials themselves, which produced much lower scores on the accuracy and completeness of the clinical evidence.

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We found that a range of techniques were being employed by POs to identify and digest the clinical evidence, some more comprehensive and systematic than others. For many POs, patient information was researched and written by a commissioned author, usually a clinical expert in the particular area. It was clear that these organisations did not have a set of guidelines which authors were asked to follow when searching for, reviewing and analysing the clinical evidence. From interviews with these POs a common theme emerged, which was that the expert writer was very familiar with the evidence in their field and that guidance from organisational staff was felt, therefore, to be inappropriate or unnecessary. However, this made it difficult to score this area given that the writers' evidence strategy could vary from drawing on their existing knowledge, through reading a select number of medical publications, to conducting a comprehensive literature search using electronic databases and library resources.[3] Moreover, while medical experts might be well placed to summarise the clinical evidence, it is unlikely that individual clinicians would be aware of all the literature that might be of importance when producing patient information unless they had specifically reviewed it. Patients, for example, may want to know about the evidence not only about conventional medical treatments but also for specialist issues such as complementary and alternative therapies, psychosocial interventions and self-help strategies.

It is not inevitable that information that is valued by patients will be neglected if the use of evidence is limited to what the expert writer thinks is important or knows about, but it makes it more likely. Relying on a single expert's opinion or knowledge has been shown to be unreliable in clinical research, let alone in the broader field of patient information (Oxman et al 2004). Furthermore, given the pace at which new research is published in some clinical fields, there is a risk that writers who do not conduct systematic literature searches will fail to include the most up-to-date and reliable clinical evidence (Chalmers 2004).

By contrast, approximately one third of interviewees described extensive literature searching procedures prior to drafting materials. It should be noted that many of these organisations are involved in evidence-based publishing for health professionals as well as patients and consumers. Consequently, they have significant in-house expertise in literature searching and appraisal, and some are also connected to other evidence producers (such as the BMA's Best Evidence, the Cochrane Collaboration or the National Library for Health). In one such organisation, the writer of a new piece of information is provided with a topic research pack which includes the materials the organisation has have produced for health professionals on the subject; systematic reviews; randomised controlled trials; official clinical guidelines; and any additional clinical evidence.

Many POs mentioned difficulties in finding reliable clinical evidence on which to base patient information. A number of important problems were identified:

- there is very little high quality evidence for certain health topics; this was most commonly mentioned in relation to the topic of obesity/healthy eating
- there is also a paucity of evidence on many issues that are of importance to patients, including new treatments, quality of life outcomes, and practical matters (eg self-help or exercise)
- there are instances where the evidence is ambiguous or conflicting.

These problems have significant implications for the accreditation scheme. Health information should, as POs themselves agree, be evaluated for clinical accuracy. Patients often want information on topics that are under-researched and advice on issues where the evidence is inconclusive, but where evidence is unavailable or unclear. Decisions have to be made by patients and clinicians, sometimes on the basis of flimsy evidence, but it is unethical to mislead people into thinking that the evidence is stronger than it is. It is essential that patient information is explicit about the degree of uncertainty, as categorical statements and didactic recommendations that

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[3] We chose to accept at face value statements from these POs about following evidence-based practices, but consequently scores for this section may be inflated in some instances. For assessment in a formal accreditation scheme, POs would need to provide detailed accounts of how expert writers find and evaluate clinical evidence.

don't acknowledge scientific uncertainty are unreliable and help no one.

The challenge of keeping information materials up to date was also frequently mentioned. POs were asked how often they reviewed the content of their materials, and the majority indicated a period of between one and three years. Many explicitly commented that maintaining currency of information was a high priority, and very few POs did not have a procedure for updating (although some noted that they weren't always able to review materials as frequently as they would like to). What also emerged was a sense of the sheer magnitude of the updating process. This meant not only keeping abreast of new research and ensuring that materials were identified for review at the appropriate time, but also making ad hoc changes in response to new developments. Some providers of arthritis information, for example, reported how difficult it had been to supply patients with the most up-to-date evidence during the time that key drug treatments were being investigated and subsequently withdrawn by the drug regulatory agency. Revising web-based information was felt to be easier, given that new versions of paper leaflets needed to be re-printed and re-distributed.

5.6 Addresses usability issues

Just as the need for information varies across the population, so too does people's capacity to read, understand and act upon that information. To reach all groups, producers may have to take into account readability issues; the provision of alternative formats for those with reading difficulties or visual/hearing impairments; and the translation of materials into non-English languages. Addressing these issues places significant additional demands on POs, but is nonetheless essential if information is going have an impact beyond traditional users, who are typically white, middle class and highly educated. Our interviews identified areas for improvement, in particular for the twelve organisations that scored two or below in this section. On the other hand, it is important to recognise the various ways in which POs are endeavouring to improve the accessibility of their health information.

Strategies for checking the readability of information were employed by the majority of POs. In most cases, organisations were either relying on informal feedback about the clarity of their existing materials or building readability into the lay review process (by asking reviewers to identify any words or issues that were unclear to them). In some cases drafts were also being scrutinised by a lay editor, who was required to re-write sections that were felt to be confusing or overly technical. Standard readability formulas were not often used, and some justified this by pointing to various shortcomings in applying these formulas and interpreting their scores. While relatively few POs had received the Plain English Campaign Crystal Mark, many more remarked that they would be keen to do so, but were unable to meet the costs associated with this. Some also reported that they followed the writing guidelines produced by the Campaign or had sent staff on writing in plain English courses. However, POs did not always appear to be assessing readability in a systematic or rigorous way, or to have materials reviewed by patients with different needs and abilities. There were exceptions to this: one interviewee, for example, reported that their organisation had used cognitive interviewing techniques to ensure materials were understandable and usable. In another, comprehension was tested with a mixed-ability patient panel and detailed readability guidelines for authors had been developed.

Many POs provided at least one alternative to written material, sometimes on request only. These included video, CD-Rom and, in particular, audiotape formats. Some also produced large print leaflets, in accordance with the Royal National Institute for the Blind (RNIB) guidelines on producing information for the visually impaired. Collaboration with organisations that could advise on accessibility issues, including the RNIB and Royal National Institute for the Deaf, was infrequently reported. Finally, many POs were keen to talk about the importance of usability issues and gave examples of development work they were undertaking to progress these.

Although very few organisations produced information in languages other than English as

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standard practice, some reported that they had translated documents in response to specific requests. In total, 14 providers received the bonus point awarded for providing non-English language materials.

5.7 Has a dissemination plan

The challenge of producing high quality patient information materials is followed by the equally difficult task of ensuring that these reach the people that need them. This involves making patients aware of information and ensuring that they can access the materials they want. It also includes promoting health information to clinicians and other professionals, and ultimately integrating information-giving into the process of clinical care. This last point is important: patients often complain that they are not given enough information or are given all the available information at once (usually following a diagnosis). The former can leave patients feeling anxious and unsure and the latter is simply overwhelming, particularly when the individual is trying to come to terms with their diagnosis. Patients' information needs change during the course of an illness. The ideal is for individuals to get the right information, for the right purpose, at the right time. POs can play a valuable role in this by encouraging health professionals to see information delivery as a component of the care that they give to their patients, and by helping them with targeted delivery of information resources that are built into the care pathway, preferably electronically.

Of all the areas assessed using section 2 of the IPDAS checklist, POs scored least well in this final one. Just two organisations achieved full marks, and some readily acknowledged that they could do more towards distributing and publicising their materials. Others commented on the difficulties of getting information to patients/carers who aren't traditional information users, or encouraging health professionals (GPs in particular) to give their materials to patients during clinical consultations. Nonetheless, almost all POs were doing something to disseminate their information, and just five organisations achieved a score of 1 (indicating that they failed to meet the criteria in any way). Commonly reported techniques included:

- national distribution of leaflets and advertising materials: for example, to general practices, NHS Trusts, health visitors, schools or organisations such as the Citizens' Advice Bureau
- mailshots to health professionals
- advertising new leaflets in the organisation's newsletter or on their website
- promotional activities such as 'leaflet of the month'
- use of mass media
- including a list of all available materials at the back of leaflets
- having websites linked to those of related organisations
- distributing through the networks of patient organisations or support groups
- providing leaflet display boards to general practices and NHS Trusts
- use of in-house email systems to promote to colleagues in other departments.

Dissemination activities in some POs were more actively targeting health professionals, for example by visiting general practices, speaking at conferences or advertising in key medical journals. Patient groups also promoted through their medical advisory boards, expert peer-reviewers or other clinical contacts.

In addition to the above, two provider organisations are currently working towards integrating their information into clinical software systems, to make it easier for health professionals to identify and give out the right information to support their patients. Both are commercial organisations that have relatively large budgets for information development.

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5.8 Views on the quality criteria

Prior to the interview, all provider organisations were sent a copy of the IPDAS assessment criteria. The version they received included only the general headings rather than the specific sub-items. The main reason for this was to preserve the open-endedness of the conversation, but we were also concerned about providing information that would unduly influence the answers given about the development process. The overall opinion of the criteria was positive, with interviewees agreeing that they covered important dimensions of information quality. A number of issues were suggested as being of particular importance including: currency of information, use of visuals/diagrams, writing in plain English, being evidence-based and clear design and layout. Some expressed concerns about the criterion 'Include methods for clarifying and expressing patients' values, priorities, motivations and barriers to change', which was felt either to be confusingly worded or unattainable. This has subsequently been revised; it is now entitled 'Helps patients make appropriate decisions' and addresses the various ways in which information can play a role in guiding patient decision-making.

When asked, many providers felt that their information materials and development process did meet these criteria or could do so with relatively little extra work. The three areas that provider organisations thought would pose the greatest challenge were the presentation of outcome probabilities in section 1, addressing usability issues and following a dissemination plan (section 2). This largely concurred with our own findings from the assessment of the development process, with the final two sections scoring less well than the former. Efforts are least focused on strategies for distribution/promotion of information, and many organisations acknowledged that this was an area that they needed to address.

However, we would also suggest that provider organisations need to improve their practice in the areas of user involvement and searching for evidence. In particular, they need to ensure that their processes in these areas are systematic, rigorous and transparent. In many cases, we found that organisations were attempting to involve users or identify clinical evidence in an ad hoc and inconsistent way. Guidelines or policies play a useful role, but these must be followed not only by information providers, but also by the people they work with (eg external authors).

5.9 Relationship between content scores and development scores

There was only a weak, non-significant correlation between scores achieved on the two sections of IPDAS (table 20). Some providers who scored high on the content of their materials did not score well on the development process, and some of those whose materials failed to reach the standard, nevertheless claimed to have a relatively high quality development process. Once again, we would stress the need for caution in interpreting these results. While we believe our assessment of the content of the materials was reasonably systematic and reliable, the same may not be true of providers' accounts of their development process for the reasons outlined in section 5.3 above.

As examples of the types of discrepancies that arose, at one extreme was the small voluntary organisation where no users were involved in the development process, the informant was unable to specify where they found their clinical evidence, their materials were targeted towards educated readers and they weren't concerned about making them accessible to less literate groups, and they had nothing approximating a dissemination strategy. Yet the content of their leaflet achieved a good score and a high ranking. At the other end of the scale, a large public sector organisation achieved a very high ranking in respect of their account of the development process, but much

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lower in terms of content assessment. This underscores the importance of an accreditation system assessing both the development process and the information content.

Table 20: Scores and rankings achieved on the two sections of the IPDAS checklist

Organisation type	IPDAS section I (content) /40	Rank (content)	IPDAS section II (development) /30	Rank (development)
Public	37.0	1	28	1
Voluntary	35.5	2	20	16
Public	34.5	3	22	11
Commercial	33.0	4	27	3
Commercial	31	5	19	18
Commercial	30.5	6	26	4
Commercial	30.5	6	22	11
Public	30.5	6	22	11
Voluntary	29.5	9	9	27
Commercial	28.5	10	12	24
Voluntary	28.5	10	24	7
Voluntary	27.5	12	24	7
Voluntary	27.0	13	20	16
Voluntary	26.5	14	21	15
Public	26.0	15	23	10
Public	26.0	15	28	1
Commercial	25.5	17	22	11
Public	25.5	17	7	28
Voluntary	25.0	19	15	21
Voluntary	24.5	20	15	21
Public	23.0	21	19	18
Commercial	23.0	21	10	25
Public	22.7	23	24	7
Voluntary	21.5	24	19	18
Public	20	25	14	23
Voluntary	19	26	25	6
Public	16.0	27	26	4
Voluntary	14.0	28	10	25

No organisational type (public, voluntary or commercial) stood out as being more or less likely to achieve high scores. There appeared to be a relationship between the size of provider organisations and the quality of the development process in that the very largest organisations scored more highly than the very smallest, but it was less clear that this applied in the middle of the spectrum as the scores of medium-sized organisations varied substantially. Those organisations that had a clear information policy tended to score higher on Section II than those that did not, but this was not invariably the case.

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6 What do people think about the proposed information accreditation scheme?

We invited people to give their views on the proposed information accreditation scheme in both the email survey of information specialists and the telephone survey of information providers. As outlined above in chapter 3, the information specialists were a mixed group that included NHS staff, academics, and people working for voluntary and commercial organisations with a specific interest in patient information. Many were actively involved both in advising patients and in developing patient information materials.

After answering our questions on the development process, information providers were also asked a series of questions to elicit their opinions on the Department of Health's proposed scheme for accrediting health information. Many provider organisations were aware of the proposals, and some had already responded to our request for comments in the information specialists' survey. We have combined responses to these two surveys in the analysis that follows. They pointed to various advantages and concerns in respect of the proposed information accreditation scheme:

Table 21: Perceived advantages and concerns re accreditation scheme

Advantages	Concerns
Improving information quality	Time and cost
Increased revenue for information providers	Adequate publicity for the scheme
Enhanced trust among health professionals	Flexibility
Greater use of information by patients and the public	The assessment process
Improved public image for information providers	Impact on smaller providers
	Independence and brand
	Sustainability

These are discussed in more detail below.

6.1 Views on the current quality of patient information

A number of respondents offered their opinions on the current quality of patient information, and there was a general consensus that it was both variable and often poor. For example, the following quote comes from a respondent working in an acute NHS trust:

> *The current level of information that is provided to patients in the NHS is very patchy, non patient friendly, and produced in more of a teacher-student fashion. It also varies in terms of quality, contents and availability, across the country.*

Some indicated that concerns about quality are largely being driven by the growing use of the internet for health information by patients and the public:

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> *There is also far too much uncritical, unevaluated and potentially misleading or dangerous information available, especially on the internet.*
>
> *There is a lot of information available, particularly on the internet and in the media, which has very little evidence base. This causes great confusion for the public with conflicting messages being given.*

However, even though the internet is seen by some as a particular problem, it is important to note that there was a general sense of concern about the quality of all types of information for patients.

Some respondents also commented on difficulties involved in accessing good quality material, identifying specific groups for whom accessibility issues are most acute. For example, one respondent suggested that the process of disseminating information materials to patients deserved greater attention that that of quality. They suggested that the lack of named individuals with overall responsibility for coordinating information provision constituted a serious problem, as is the frequent failure of hospitals to allocate budgets for the purchase of good quality materials. Another noted that too many patients do not receive appropriate information at the time of diagnosis, nor are they given contact details for appropriate voluntary organisations. The variability in clinicians' skills in identifying and addressing patients' information needs was identified as a major cause of this problem. A number of respondents also highlighted the importance of addressing accessibility for patients with visual or hearing impairments, learning disabilities or who do not have English as their first language. Some cautioned that an accreditation scheme should have the interests of all patients at its centre, not just those with relatively straightforward needs.

6.2 Advantages: improving information quality

Overall, most people reacted positively to the idea of an information accreditation scheme. None of the information specialists explicitly stated that they were against such a scheme, and most of those who did comment felt that accreditation in principle could have a valuable role in regulating and improving the quality of patient information. For example:

> *Consistent, quality information clearly has a pivotal role in improving health and empowering service users. A system that ensures these standards would be welcomed.*
>
> *An accreditation scheme could be a useful tool if it served to eliminate the huge variation in the standard of patient information.*
>
> *Quality standards would be a way of assuring quality in the production of patient information and would give greater confidence to users who need to know that what they are being told has credibility.*

The majority of provider organisations felt that, in principle, the accreditation scheme was a good idea and could potentially function to improve the quality of health information. Moreover, there was agreement that the focus on this area was warranted, given that there is currently substantial variation in the quality of information available to patients. Many interviewees expressed concern about information sources that are inaccurate, misleading or unbalanced, and hoped that an accreditation scheme may discourage patients from using these. But some also questioned the motivation for introducing a scheme of this type, and questioned whether this was being driven by patient-defined needs and interests.

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6.3 Advantages: increased revenue for information providers

Only two of the provider organisations whose material we assessed currently make a direct charge for access to their information (EIDO and Treatment Notes). A further five organisations include advertisements on their websites (Babyworld, Channel 4, Home Health UK, Medic8 and Net Doctor). Nevertheless, a number of interviewees believed that their organisations might benefit from increased revenue as a result of accreditation. The not-for-profit provider organisations among these, however, were keen to point out that this would not be their motivation for applying for accreditation, but rather that it would be seen as an added bonus. Providers envisaged that their financial situation would improve because:

- they could sell accredited information to patients or healthcare providers (eg NHS Trusts)
- there would be increased interest among companies to advertise on the website of an accredited organisation (commercial organisations only)
- they would gain competitive advantage over other non-accredited information providers (commercial organisations only)
- they may attract more donations/legacies or offers of sponsorship (not-for-profit organisations only).

6.4 Advantages: enhanced trust among health professionals

Some providers believed that accreditation would improve their reputation among health professionals. They thought a mark of quality assurance from an official body would encourage health professionals to trust their information materials and, consequently, to distribute it to their patients.

6.5 Advantages: greater use of information by patients and the public

Certainly, some organisations were sceptical about whether patients would be more likely to use quality assured sources of information, but many others hoped that achieving accreditation would increase demand for their materials. Interviewees noted that patients wanted information that they could trust and that the scheme would be a useful vehicle for achieving this. The benefits would be both to patients: who would have increased access to the best sources of information, and to provider organisations: whose information would reach a wider audience.

6.6 Advantages: improved public image

The reputational effects of accreditation are not straightforward. Some of the bigger and more well-known provider organisations felt that official recognition would add little to their already high status among patients. However, this view was not universal among those we spoke to and others envisaged that their public image would be enhanced as a result of receiving accreditation. Interestingly, some interviewees at NHS Trusts commented that this could have knock-on benefits in terms of attracting patients under the ‘Choose and Book’ system.

6.7 Advantages: recognition of best practice

Some provider organisations felt they were leading the way in producing high quality patient information, and were keen to have accreditation in recognition of this.

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As well as the above potential benefits of the Department of Health's proposed scheme, two other reasons were given for applying for accreditation. The first was if all an organisation's competitors had achieved accreditation, and second was if the Department of Health/NHS committed to centrally purchasing quality assured materials.

6.8 Concerns: time and cost

Enthusiasm for an accreditation scheme was not unqualified, however. A number of provisos or considerations were mentioned, that were felt to be important to scheme's successful operation and its potential to improve information quality. Of all the concerns, that of cost was predominant. Unsurprisingly, it was respondents from voluntary sector and NHS organisations that suggested a potential problem in meeting the costs associated with accreditation. On this issue, two respondents commented:

> *I agree [information accreditation] is a good idea, the only proviso I would add is that the majority of palliative care is delivered by the voluntary sector which doesn't have publication departments or many funds. Therefore any scheme needs to take into account how achievable it is to achieve accreditation with these restrictions and how small charities can afford to make information to the standards with no funding for this.*
>
> *[My organisation] already spends £400,000 a year on preparing and publishing information for people with [condition] and those associated with them. Our free helpline has recently gained Telephone Helplines Association accreditation. Currently only some 3% of THA members are accredited and this is almost certainly because of the costs involved. The £3000 accreditation fee is sufficient to disbar many smaller organisations from applying: the additional costs associated with seeking accreditation (we estimate 4 months work) seriously militates against greater numbers taking this route. Costs therefore will be a significant factor in determining the success of any accreditation scheme, particularly if the Government will want to tap into the rich seam of user-developed health and social care information produced by the voluntary sector.*

Another respondent, working in an acute trust, also expressed doubt about whether their trust would be able to afford accreditation. Given this, they suggested that a national database of high-quality leaflets would be more useful than an accreditation scheme. This would also serve to eliminate the current duplication of effort in the production of patient information across the NHS.

Many respondents from provider organisations felt that substantial additional time and resources would be needed to fulfil the requirements of accreditation – both in terms of bringing materials up to the required standard and completing the application process – and expressed concerns about their ability to meet these demands. Interviewees were specifically asked if organisations should pay for accreditation. Responses were mixed, but there was a general sense that a high fee would effectively restrict accreditation to larger, better resourced organisations. It is also important to note that many provider organisations are already working with restricted budgets and will struggle to find additional money for quality improvement and/or an accreditation fee. Some proposed a graded fee, with lower rates for not-for-profit and public organisations and higher ones for commercial equivalents. Others felt that a fee should not be charged, and that the Department of Health should financially support the accreditation scheme as part of its commitment to improving access to health information.

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A further consideration was the time it would take organisations to achieve accreditation. One or two respondents were concerned that the production of patient information might be delayed or hampered while providers undertook the various activities required for obtaining accreditation.

6.9 Concerns: adequate publicity for the scheme

After time and cost, the issue that was most often raised was the importance of substantial and ongoing awareness raising activities. Many provider organisations stated that a public marketing campaign was crucial if accreditation was going to have the desired effect on the availability and uptake of high quality health information. Some would be cautious or unwilling to apply for accreditation if they felt that the public were not sufficiently well informed about the existence of quality assured information, and where and from whom to obtain this. Thus accreditation was seen as a partnership between provider organisations and the Department of Health, with each fulfilling their respective responsibilities: provider organisations to develop good quality information and the Department of Health to encourage the public to look for and use this where available.

Raising awareness of accreditation among both patients and those who deliver information (eg clinicians, librarians) was seen as essential if accreditation was going to have the desired impact. This point was raised by the Public Health Information Representatives Forum (PHIRF), which consulted all its members on the proposed scheme before submitting a joint response to the Picker Institute. However, the PHIRF went on to suggest that the aims of the accreditation project would be more effectively served by a national strategy to improve health literacy:

> *In an era where informed decision-making and individual responsibility for health are being encouraged, a focus on imparting transferable information literacy skills to all seems to be the most compatible approach.*

A health literacy training programme, it was noted, could be delivered by services already involved in signposting high-quality patient information and imparting literacy skills – such as public libraries, healthy living centres and public health information services.

6.10 Concerns: flexibility

Along with cost, issues around flexibility were also frequently raised. Generally, at issue was the extent to which national standards could be balanced with the development of information to meet local or specific needs. Implicit in the comments was a fear that accreditation would not only reduce variability of quality but encourage homogenisation and stifle creativity. This fear was explicitly stated by two respondents:

> *I hope any system which is developed does not strip away each charity's individuality and uniqueness of approach.*
>
> *The anger with these schemes of course if that they can become extremely prescriptive with a 'one-size-fits-all' approach, which can stifle innovative and creativity.*

The second respondent offered the Plain English Campaign's Crystal Mark scheme as an example of an accreditation scheme that was not unduly restrictive. This scheme judges documents against certain principles but, assuming that the information is factually correct, takes in account their specific purpose and intended audience when making a final decision. However, another respondent questioned the appropriateness of the Crystal Mark scheme to health information. Their organisation chose not to follow recommendations made by the Plain English Campaign, as these were felt not to correspond to their own opinions about the needs of their target audience.

6.11 Concerns: the assessment process

Closely linked to the issue of flexibility was a set of concerns about the accreditation process itself, and in particular the tool or checklist that would be used. A detailed response was given by one organisation, which had previously developed a patient information booklet that had received considerable commendation from both patients and other bodies (eg the BMA and a leading charitable organisation). They submitted the leaflet for accreditation by CHIQ, but it was rejected because its DISCERN score was too low. The problem was not with the quality of the leaflet, nor its usefulness to patients, but that it did not cover all of the items addressed by the DISCERN tool. In view of this, the respondent suggested that the criteria for assessing materials should take into account what patients deem to be important, which may not always conform to standardised items set by researchers.

Another respondent was concerned that assessment tools tend to focus on the format of materials, and exclude items which would scrutinise the usefulness of the information contained:

> *Although numerous tools have been developed to both assess and guide the production of information, much of it cannot actually check the information for accuracy and relevance. Many of the tools are also only concerned with format, design and readability.*

However, this comment is not relevant to the IPDAS checklist used in our study, since it includes items covering all the above mentioned domains. We also collated clinical evidence on the four health topics, in order to assess accuracy.

Interviewees often commented on the vast range of information that is produced for patient use and by organisations with differing values, approaches (eg medical, psychological, social) and objectives. Many respondents suggested that a degree of flexibility was needed in applying the criteria in order to maintain and encourage this diversity. A one-size-fits-all approach was strongly cautioned against, given that this would serve certain interests and approaches and potentially undermine others. The problem of identifying clinical evidence was also raised in this respect, with some provider organisations commenting that the paucity of good research in their area would make it difficult for them to show how their development process met the 'up-to-date scientific evidence' criterion. It was felt that this issue could only be fairly judged if wider contextual issues were taken into account.

A number of provider organisations were concerned that accreditation would become a 'hoop-jumping' or 'tick box' exercise, rather than functioning as a lever for meaningful quality improvement. While the criteria were broadly accepted by interviewees, some identified dimensions that would be difficult to incorporate into an accreditation process because of the difficulty of defining, targeting and measuring them (eg how well information reflects patients' experiences of care). It was suggested that accreditation may encourage provider organisations to concentrate their improvement efforts on the formal criteria, rather than taking a broad and creative approach to meeting patients' information needs. On a related point, NHS Trusts have to produce information in compliance with Clinical Negligence Scheme for Trusts (CNST) standards. To ensure that accreditation did not simply represent another layer of 'red tape', Trust-based interviewees pointed out, the scheme should be developed in accordance with these existing requirements.

6.12 Concerns: the impact on smaller providers

Concerns were expressed about the future of organisations that would not be able to apply for accreditation (for example, because of the costs involved) or whose materials did not meet the required quality standard. There was a general sense among a number of interviewees that many smaller organisations produce information which is valued and needed by patients, even though it may not be of the highest quality (as defined by the IPDAS criteria). For some conditions or issues, there are often only one or two organisations producing information for patients. These provider organisations should be encouraged to continue their activities even in the absence of accreditation, otherwise patients would be left with no information at all. One interviewee commented: “information that isn’t accredited is better than no information at all.”

6.13 Concerns: independence and brand

A main proviso for supporting an accreditation process was that the scheme be fairly and responsibly managed. We had anticipated many of the concerns that provider organisations had about the accreditation scheme, but not the issue of branding and corporate identity that was discussed by a number of interviewees. Many of the larger patient groups and some public organisations felt that their organisational ‘brand’ already had a good reputation among the general public. In particular, they stated that their information was highly trusted by patients because it was strongly associated with quality and reliability. This had two consequences; some of these provider organisations thought that accreditation was unnecessary given the trusted nature of their own brand. Others weren’t ruling out the possibility of applying if a scheme were set up, but were concerned that an accreditation logo would conflict with or detract from their own brand or simply confuse patients. Furthermore, as one interviewee pointed out, organisations producing printed materials would incur substantial costs because they would have to re-print materials to display the accreditation mark.

A small number of respondents specifically raised concerns about the potential involvement of the NHS/Department of Health, and suggested alternatively that the accreditation scheme be operated by an independent body. For example:

> *Any accreditation scheme would also need to be independent of the NHS for private organisations to take it up. There was only limited interest in the earlier "NHS approved" scenario, for example.*

However, most respondents who raised this issue were only concerned that those in charge of the scheme (whoever they may be) did not pursue “personal agendas” and acted impartially. Accreditation would have to be controlled by a disinterested party, it was felt by some, otherwise a ‘kitemark’ would be no guarantee that patient information materials were free of bias.

Some respondents felt the accrediting body should be an organisation that was known and trusted by the general public, with sufficient stature and reputation to promote public confidence in the scheme. If this organisation was highly regarded by patients, then it would be more likely that they would alter their information-seeking habits towards officially ‘kitemarked’ information.

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6.14 Concerns: sustainability

Finally, replies also touched upon the issue of the scheme's sustainability. A number of respondents worked for organisations whose patient information had received accreditation from the Centre for Health Information Quality (CHIQ). Many of these made negative comments on the closure of the CHIQ scheme and the short-lived advantages of achieving accreditation. For example:

> *We were CHIQ partners and had just paid for, and undergone, our 2nd year appraisal when CHIQ folded.*

6.15 Examples of existing quality assurance processes

Although the survey of information specialists did not specifically request this information, a number of respondents provided details of quality assurance processes that their own organisation is developing or using. It is important to take account of these comments, because due consideration must be given to how a national accreditation scheme can enhance and support, rather than duplicate or compete with, the activities of individual information producers. These responses also cogently demonstrate the importance of setting and raising quality standards to those involved in producing and dissemination patient information.

Of the quality assurance processes referred to by respondents, the first level was that of a set of standards which must be met by all newly developed or distributed materials. In-house and externally produced standards were described, with the latter including the DISCERN checklist and the E-Europe Quality Criteria for Health Information. The use of such standards was chiefly mentioned by a number of people working in NHS trusts. The next level was to have materials assessed for quality at draft stage. Groups involved in this assessment process included staff members (eg in NHS trusts), clinical experts or patients and service users. Patient feedback was gathered by a range of methods including questionnaires, focus groups, patient panels, or a combination of these. In some cases, PPI forum members had been informally asked to comment on draft copies. In another trust, a patient information steering group had been set up to review all leaflets produced internally. In some cases, materials were sent to more than one type of group to get a balance of perspectives. For example, some respondents indicated that their materials were customarily reviewed by both by clinical experts and relevant patients.

At the third level, a small number of respondents demonstrated more extensive quality assurance processes: from pre-production to post-publication. This includes involving patients in the initial selection of topics and issues. For example, one respondent (working in a voluntary association) stated that:

> *Our own publications are produced on the basis of research conducted with people with [condition] on areas they identified as needing information in. The topics identified are then scoped, researched against the evidence base and prepared in outline for comment by people with [condition] and relevant professionals.*

The use of clinical evidence in the preparation of materials was also mentioned by other respondents. Some made a general claim about striving to produce evidence-based materials, but did not indicate how they achieved this in practice. Few respondents explicitly referred to quality assurance processes employed after materials had been produced and disseminated. Two

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respondents noted that their organisations (one voluntary, one commercial) regularly reviewed and updated their publications. Another explained that their voluntary organisation is moving towards assessing the impact of their patient information:

> *We are about to introduce some quality indicators to monitor outcomes and find out what people do once they have read our information.*

An example of this most advanced level was provided by a respondent from an NHS acute trust which is currently reviewing the way it produces information for patients. As part of this, patients have been asked for their thoughts about existing information and how they would like to receive information (eg internet, audio), with new templates and information prescriptions being developed on the basis of this consultation.

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7 Conclusions

This brief three-month study aimed to cover a great deal of ground, including reviewing the evidence on patients' information needs and where they look for health information; establishing and quantifying the benefits of investing in the production and dissemination of good quality health information; describing the number and types of information providers; determining the quality of currently available materials and the process by which they were developed; and seeking views on the proposed information accreditation scheme.

7.1 Benefits of health information

Good quality health information is essential for greater patient involvement in healthcare. Patients and the public require information that is timely, relevant, reliable and easy to understand. This is an essential component of any strategy to promote health literacy, self-care, choice, shared decision-making, medication adherence and self-management of chronic disease.

We established that patients want information for a variety of purposes and some go to considerable lengths to obtain it. We found many studies demonstrating the benefits to patients of good quality information, including evidence of impact on patients' knowledge and recall, improvements in their experience of healthcare and involvement in decision-making, some evidence that investment in patient decision aids is cost-effective, and some limited and sometimes conflicting evidence that information can help improve health outcomes.

Although many patients look for health information on the internet, some feel overwhelmed by the volume and variability of the information it contains. It is important to ensure that users are able to identify quality-assured internet information.

Simplifying written materials can improve readability for those with low health literacy, but health information for these groups may be more effectively delivered by non-traditional (eg visual and interactive) media. There are many benefits to patients from using computer-based information and support packages, including improved knowledge, health behaviours and clinical outcomes. These can be particularly beneficial to disadvantaged and at-risk populations, if technology access and user support are in place.

To successfully participate in clinical decisions, patients need information about their care and treatment options, and doctors must be able to work collaboratively and communicate effectively with their patients. There is good evidence that decision aids are effective tools for facilitating informed patient involvement in clinical decision-making and improving uptake of screening services. Contrary to concerns, informing patients and involving them in clinical decisions does not drive up demand. Rather, patients using decision aids tend to have more realistic expectations of treatment outcomes and often choose less invasive and expensive procedures resulting in increased cost-effectiveness.

So better information can contribute to a wide range of desirable goals, but information on its own is not sufficient to achieve an effect. The context in which it is made available and used, together with appropriate support and encouragement from health professionals, are fundamental to its effectiveness. It will be important, therefore, to consider the arrangements for disseminating the information and the circumstances in which it is to be used when calculating its cost-effectiveness and the likely impact of an accreditation programme.

7.2 The information providers

We identified 237 organisations that between them provided 285 patient information materials on the four case study topics: COPD, arthritis, healthy eating and MMR vaccination. Of these, 43% were from the public sector, including healthcare, 30% were from the commercial sector and 27% came from voluntary sector organisations. The majority (87%) provided information on only one of the four clinical topics that we reviewed.

Our statistical review identified approximately 60,000 organisations that were providing health information to the public, but gauging the proportion that might be interested in an information accreditation scheme is difficult. It is likely to be considerably lower than this, perhaps less than 7,000 organisations.

7.3 Key findings from the assessment of information materials

The revised IPDAS checklist proved to be a useful tool for assessing the quality of the information. Using this measure revealed wide variations in quality. Materials tended to score reasonably well on clarity of structure and layout, having a clear statement of aims and including information on the date of publication. They performed significantly worse in relation to the provision of accurate, reliable and sufficiently detailed clinical information to assist patients in decision-making. In particular, few materials included a clear presentation of the likely outcomes of treatment, few mentioned clinical controversies or uncertainties, and many failed to acknowledge the patient's decision-making role.

There were no significant differences between categories of providers in the quality of information produced, nor were there significant differences between the four clinical topics. The range of quality scores was wide in all categories. Paper-based material generally scored more highly than information from websites.

7.4 Key findings from the assessment of the development process

Many organisations found it difficult to give, or were unwilling to give, a detailed account of their annual expenditure on patient information materials. Estimates ranged from £2,000 to £6,000,000. They also gave a wide range of estimates of the numbers of users of their information, ranging from 8,000 to 13.5 million per year.

Most information provider organisations were committed to the concept of involving users (patients, carers, members of the public) in developing and evaluating their materials, but there were wide differences in the way they tried to achieve this. Many had no systematic process for user involvement and some appeared to over-estimate the amount of involvement they had achieved.

As with user involvement, almost all provider organisations tried to ensure that their material was evidence-based. However, the review of the materials suggested that in many instances this was very far from the case. Many organisations contracted the writing of the material to a single clinical 'expert' without developing guidelines for the process of evidence review, relying instead on his/her judgment.

However, one third of those interviewed about the development process described extensive literature searching procedures prior to drafting materials. Many of these had links to bodies producing evidence for clinicians. It is clear that the task of ensuring that information materials are based on reliable reviews of the most up-to-date research evidence is one that many provider organisations find daunting.

Most provider organisations had adopted strategies for assessing the readability and usability of their materials, but these were often neither systematic nor rigorous.

Somewhat surprisingly given that they had gone to considerable lengths to develop patient information materials, many organisations had given insufficient attention to the task of disseminating these. Many organisations said they found it very difficult to publicise the existence of their information materials to patients and clinicians.

There was widespread support for the IPDAS quality standards used in the study. Many providers felt they could meet the standards with little extra work, although this might be considered somewhat optimistic, especially in relation to improving the quality of the clinical information. The areas that they said they would find most difficult were those that related to presentation of outcome probabilities, addressing usability, and following a dissemination plan.

7.5 Opinions on the proposed accreditation scheme

Most respondents to our surveys agreed that the quality of patient information was variable and often poor, and most reacted positively to the idea of an information accreditation scheme. Perceived advantages included improved information quality; increased revenue for information providers; enhanced trust in the information from health professionals; greater use of the materials by patients and the public; improved public image for the information providers; and wider recognition of best practice.

Concerns about the proposed scheme included worries about the likely costs and the time required to prepare for and undergo accreditation; a desire to ensure that it would be adequately publicised and a fear that it would fail if not; a plea that it should be sufficiently flexible to accommodate a wide range of types of information; worries about the possible impact on small providers; concerns about independence and branding; and a concern that it should be well-established, well-managed and long-lived.

Overall, the time appears to be ripe to develop an information accreditation scheme and most people would welcome it, but its success will depend on tackling the many potential problems and ensuring that all stakeholders have a chance to shape its development.

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9 Appendices

Appendix 1: survey of information specialists

Quality of health information for patients and public

Dear Colleague,

I'm writing to ask if you'd be willing to help us with a study of the quality of health information that we're carrying out on behalf of the Department of Health.

The White Paper *Better Information, Better Choices, Better Health* proposed the development of a national Information Accreditation Scheme to give members of the public "a clear set of quality criteria covering currency of information, its reliability, user involvement in development, and accessibility". In developing the business case for the scheme, the Department of Health has asked the Picker Institute to carry out a study to determine the current quality of health and social care information to enable an assessment of the costs and added value of accrediting information providers.

We've been asked to produce an estimate of the number and types of information providers offering information on four specific diseases or conditions:

- chronic obstructive pulmonary disease (COPD)
- arthritis
- healthy eating to prevent or reduce obesity
- measles, mumps and rubella vaccination (MMR).

We want to obtain copies of relevant information materials (or website links) so we can find out more about how they were developed (by surveying information providers) and assess them against a quality checklist. We're interested in information developed specifically for patients or members of the public by UK-based commercial organisations, voluntary groups, NHS and other healthcare providers, professional or government organisations.

If you know of any information materials on any of the four topics listed above (leaflets, audio, video or websites), we'd be enormously grateful if you could either send us a copy (or a weblink) or tell us who produced it, where it's used and how we could obtain it.

We would also be very interested to hear your views on the proposed information accreditation scheme, its pros and cons and whether you think it will help to raise quality standards. Indeed, we'd also be very interested to know what you think about the current quality and availability of information for patients. Comments that are included in the final report will be anonymised and not attributable to any named individual.

Thank you in advance for any help you're able to give us.

Please respond by emailing me at Danielle.swain@pickereurope.ac.uk.

Appendix 2: survey of information providers

[Prior to interview, providers will have been sent a letter briefly outlining the study and enclosing a copy of the quality criteria – see page 4 below]

I'm calling from the Picker Institute [explain who we are if necessary], to ask if you would help us with a study we are conducting on behalf of the Department of Health. The study is aiming to determine the current quality of health and social care information, as well as assessing the viability of a national information accreditation scheme. Its finding will be used by the Department of Health to develop a business case for the scheme. We've identified a number of information providers who we'd like to speak to, including [provider]. Would you be willing to tell me about your information development process and give your thoughts on the proposed scheme - I anticipate that this will take no longer than half an hour?

First, could you give me a little bit of background information about [provider] and how long you have been producing information for patients?

Do you have a written statement of your information development process?

Section 1: The development process (IPDAS assessment)

There's a wide variety of information that patients might need to make decisions about their health or treatment – how do you choose which topics and issues to address?

Probes

- *How do you find out what patients' information needs are?*
- *Are there opportunities for patients and health professionals to be involved in the development process? [Ask for details]*

Once information materials have been drafted, what procedures do you have for reviewing them?

Probes

- *Do you ask patients to field-test or read over draft materials?*
- *Are draft materials reviewed by health professionals?*

[Where appropriate] Do you find that changes are often made on the basis of expert review/patient feedback?

Probes

- *Are there situations in which you wouldn't make changes based on comments from patients/professionals?*

Thinking about the medical content of the information, what research do you do prior to drafting the materials?

Probes

- *Where and how do you look for the research evidence?*
- *Do you find any sources of evidence particularly useful when preparing materials?*
- *How easy it is to find research evidence for the topics you're covering?*
- *Are there topics where it has been difficult to identify relevant research evidence?*
- *Have you found it possible to produce evidence-based information on [condition]?*

Given the rate at which new research is being published, how easy do you find it to keep the content of your patient information up to date?

Probes

- *Do you have a process for revising and updating information materials?*
- *What length of time do you tend to leave before reviewing the content of information patients?*

How do you ensure that patients are able to easily read and understand your information materials?

Probes

- *Do you test materials for readability? [Ask for details]*
- *Do any of your materials have the Plain English Crystal Mark?*
- *Are materials field-tested by patients with different needs and abilities?*
- *Do you produce information in alternative formats or languages?*
- *How do accessibility issues shape the information development process?*

Once materials have been developed, do you have any methods for ensuring that the information gets to patients that need it?

Probes

- *How is your information distributed?*
- *How are your leaflets/website publicised?*
- *Have you found any effective ways of promoting your information to health professionals?*
- *Have you received feedback from patients or health professionals on your information?*

Section 2: Opinions on accreditation/quality standards

We recently sent you a set of quality criteria for patient information. How useful do you think these criteria would be for assessing the quality of patient information?

Probes

- *Do these criteria cover all the important aspects of information quality?*
- *Is there anything else you would add to them?*
- *Do you like the idea of having two sets of criteria – one relating to the content of materials and the other to the development process?*
- *What do you think about the current quality of patient information?*

An accreditation scheme has been suggested as one way of maintaining and improving the quality of patient information. What do you think about the idea of accrediting patient information?

Probes

- *What impact do you think accreditation would have on the overall quality of patient information?*
- *How do you feel about a scheme that would accredit provider organisations rather than individual pieces of information?*

If an accreditation scheme was established using the quality criteria we sent you, do you think [provider] would be likely to apply?

Probes

- *Is there anything in particular which would discourage you from applying?*
- *Are there any circumstances under which you wouldn't apply for accreditation?*
- *What benefits would you expect [provider] to gain from achieving accreditation?*
- *Do you already have any form of accreditation for your patient information? Would this affect your interest in applying for accreditation through a new scheme?*

Do you think it is feasible to ask information providers to pay for accreditation?

Probes

- *If accreditation cost [£500/£1000 etc], would you organisation be likely to apply?*
- *Is there a cost level at which [provider] would be discouraged from applying?*
- *What benefits would accreditation have to bring for a fee to be acceptable?*

Looking at the quality criteria, is there anything that [provider] would need to do in order to meet the standards for accreditation?

Probes

- *Are there any particular areas or issues which might need attention before applying for accreditation?*
- *Can you think of any support needs you might have in working towards the standards for accreditation?*

Appendix 3: materials selected for detailed assessment

1. Arthritis

	Provider	Name	Resource	Access
1	Arthritis Care	Living with osteoarthritis	Leaflet	Copies available
2	Arthritis Research Campaign	Introducing arthritis	Leaflet	Copies available
3	Nottingham City Hospital	A patient's guide to shoulder joint replacement	Leaflet	Copies available
4	EIDO	Total hip replacement	Leaflet	Copies available
5	BBC	The arthritis guide	Website	http://www.bbc.co.uk/health/conditions/arthritis/
6	NHS Direct Online	Arthritis (Health Encyclopaedia)	Website	http://www.nhsdirect.nhs.uk/en.aspx?articleID=32
7	Bradford Teaching Hospital	Joint Action: information for patients	Leaflet	Copies available
8	Home Health UK	Rheumatoid Arthritis	Website	http://www.homehealth-uk.com/index.html?f=body|fr=http://www.homehealth-uk.com/medical/rheumatoidarthritis.htm|r
9	AXA PPP Healthcare	Rheumatoid Arthritis	Website	http://www.axappphealthcare.co.uk/maia?h=fam_head&f=factsheet_footer&p=consumer/fam_hc&u=fam_utility&n=consumer/health_atoz&t=rheumatoid_top&b=shared/fact_sheets/rheumatoid/rheumatoid
10	National Anklylosing Spondylitis Society	Questions you may have	Website	http://www.nass.co.uk/questions.htm

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	Provider	Name	Resource	Access
11	Department of Health	MMR Discussion Pack	Leaflet	Copies available
12	MedInfo	MMR Vaccination	Website	http://www.medinfo.co.uk/immunisations/mmr.html
13	DIPEx	Immunisation: making the decision	Website and multimedia	http://www.dipex.org/immunisation
14	Treatment Notes	Should children have MMR?	Leaflet	Copies available
15	Health Education Board for Scotland (now NHS Health Scotland)	MMR Discussion Pack	Leaflet	Copies available www.hebs.com/services/mmr.pdf/mmrdiscussion.pdf
16	Bandolier	MMR Vaccination	Website	http://www.jr2.ox.ac.uk/bandolier/band84/MMR.html
17	Babyworld	Explaining MMR	Website	http://www.babyworld.co.uk/features/mmr/measles_mump_rubella.htm
18	Science Museum	The MMR Files	Website	http://www.sciencemuseum.org.uk/antenna/mmr/
19	Van UK – Vaccine Information Service	MMR Factsheet	Website	http://www.vaccine-info.org/ (click 'Vaccine Info', select MMR from click down list – this will bring you to the MMR Factsheet)
20	Medic8 Family Health Guide	MMR Vaccine: a patients guide	Website	http://www.medic8.com/healthguide/articles/mmrvaccine.html

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	Provider	Name	Resource	Access
21	British Lung Foundation	Living with COPD	Leaflet	Copies available
22	Boehringer Ingelheim	Living with COPD	Leaflet	Copies available
23	Chest, Heart and Stroke Scotland	Living with COPD	Leaflet	Copies available
24	Prodigy	COPD: patient information leaflet	Website	http://www.prodigy.nhs.uk/ProdigyKnowledge/PatientInformation/Content/pils/PL33.htm
25	South Warwickshire PCT/South Warwickshire General Hospitals NHS Trust	Pulmonary Rehabilitation Book	Leaflet	Copies available
26	Department of Respiratory Medicine, New Cross Hospital, Wolverhampton	COPD	Leaflet	Copies available
27	York Hospitals NHS Trust	Living with COPD: information for patients	Leaflet	Copies available
28	North Tees and Hartlepool NHS Trust	COPD: information for patients	Leaflet	Copies available
29	Channel 4	Chronic lung disease	Website	http://www.channel4.com/health/microsites/0-9/4health/body/ill_lung.html
30	BUPA	Chronic bronchitis and emphysema	Website	http://hcd2.bupa.co.uk/fact_sheets/html/COPD.html

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	Provider	Name	Resource	Access
31	Food Standards Agency	Obesity (Eat Well, Be Well)	Website	http://www.eatwell.gov.uk/healthissues/obesity/
32	British Heart Foundation	So you want to lose weight…for good	Leaflet	Copies available
33	University Hospitals Coventry and Warwickshire NHS Trust	Weight loss, food facts and tips	Leaflet	Copies available
34	National Obesity Forum	The public	Website	http://www.nationalobesityforum.org.uk/apps/content/html/ViewContent.aspx?fid=1542
35	Best Treatments	Obesity	Website	http://www.besttreatments.co.uk/btuk/conditions/12911.html
36	Ipswich Hospital Trust	Want to tackle your weight/Want to lose weight	Leaflets	Copies available
37	NICE	Guidance on the use of orlistat for the treatment of obesity: information for patients	Leaflet	Copies available
38	British Dietetic Association	Weight Wise	Website	http://www.bdaweightwise.com/bda/
39	Net Doctor	Obesity	Website	http://www.netdoctor.co.uk/health_advice/facts/obesity.htm
40	Weight Concern	Losing Weight	Website	http://www.weightconcern.org.uk/ (all the pages under the 'Losing Weight' section)

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