

# Section 5

## Further information



# A review of other resources

Ms Margaret Martin, Dr Lucy White

## Introduction

The provision of information for patients is an integral part of patient care. It appears in policies for clinical governance and for research programmes. Improving communication with patients and enhancing their ability to be partners with professionals in their own health care is a key component of the NHS Plan.<sup>1</sup> ‘Patient and Public Involvement in the new NHS’<sup>2</sup> states that public involvement must occur in every part of the NHS. It should be genuine and not tokenistic, engaged and listening. This will require commitment and cultural change.

## The consent process

Government and professional bodies generally agree that there are strong moral and ethical reasons for involving people in decisions about their care and treatment options. The report of the public inquiry into children’s heart surgery at the Bristol Royal Infirmary (Kennedy Report)<sup>3</sup> and The Report of the Royal Liverpool Children’s Inquiry<sup>4</sup> both made far-reaching recommendations about involving patients and parents in treatment decisions and made it clear that they should be given full information to support that involvement.

Enabling patients to make healthcare choices that are right for them, and recognising that different patients will make different choices has had implications for consent procedures in the NHS. The Department of Health consent initiative<sup>5</sup> points to the importance of making written information available to patients on their treatment options, to back up verbal information given during a consultation. If patients do not receive enough information on which to base their decision, then the consent may not be valid. A recent case heard at the court of appeal demonstrates this point.<sup>6</sup> The GMC has issued guidelines to help doctors inform their patients.<sup>7,8</sup>

## Informing patients – does it make a difference?

There is growing research evidence that involving patients in treatment decisions can lead to:

- improved health and well being of patients, by promoting active partnerships with health professionals
- better treatment outcomes
- improved doctor patient relationships
- more responsive and targeted health services
- a more focused research agenda by identifying issues which are important to patients.

It is also evident that many patients are ready and willing to explore treatment options and to share decision making.

This literature review acts as a resource guide to back up these statements. The first five sections refer to health care in general and the final section discusses information for anaesthesia.

## Shared decision making

A shared decision has been described by Charles et al, and involves:

- information exchange
- a deliberation process
- a treatment decision.<sup>9</sup>

An informed decision is also described as:

*‘One where a reasonable choice is made by a reasonable individual using relevant information about the advantages and disadvantages of all possible courses of action, in accord with the individual’s beliefs.’<sup>10</sup>*

Informed decision making can only happen when the patient receives information on all available options, benefits, risks and potential complications.<sup>9,11,12</sup> There are some indications that shared decision making can have a positive influence on patients’ health, although this is still being researched.<sup>13</sup>

The literature shows that although most patients want information about their disease and its treatment, some of those same patients do not want to take part in decision making.<sup>11</sup> The decision-making process must offer patients the choice of participation and of non-participation.<sup>11,12</sup>

Decision aids exist which have been shown to improve knowledge, reduce decisional conflict and stimulate patients to be more active in decision making without increasing their anxiety.<sup>14,15</sup> Charles identifies three predominant models of decision making (paternalistic, shared and informed) and advocates a flexible approach so that individual differences in patient preference can be respected.<sup>16</sup> Entwistle argues that no single model for shared decision making should be advocated and that there is still a lot to be learned about the different approaches:

*‘Policies promoting patient participation in treatment decision making need to be flexible enough to ensure that they are appropriate across the range of contexts in which health care decisions are made and acceptable to people with diverse preferences and abilities.’<sup>17</sup>*

If patients want to be involved in decision making, health professionals need to be able to meet their information needs. However, even skilled health professionals, up-to-date with the best evidence, may not have the time in a consultation to convey all the information needed for shared decision making. Good quality written information, which outlines treatment options, is a key way of overcoming this problem. Coulter and colleagues identify the information deficit:

*‘Current information materials for patients omit relevant data, fail to give a balanced view of the effectiveness of different treatments, and ignore uncertainties.’<sup>18</sup>*

Several resources exist which describe the practicalities of producing and evaluating good quality information materials.<sup>19,20,21,22</sup> An important theme is the involvement of patients in the development process. One study shows major deficiencies in information materials, particularly with respect to the mention of choice, risks, uncertainties, the effect of no treatment, and the identification of the evidence base for the information.<sup>23</sup>

Another useful aid to shared decision making is the provision of a recording or a written summary of key consultations. This was the subject of a Cochrane review which concluded that this is beneficial to most adults.<sup>24</sup>

## Patient involvement and patient groups

Coulter discusses the importance of patient involvement in the development of information materials.<sup>18</sup> A useful outline of the arguments for setting up professional/consumer groups to deal with health care issues in general is found in two recent papers.<sup>25,26</sup> Included in these papers is the idea that three different types of consumer may contribute vitally to such a working group. Past or present patients may speak only based on their own experiences. Members of a patient group may be able to speak for the experiences of the group of which they are a part, (for example a forum for people with a disability, or people with a mental illness). Thirdly, patient representatives are experts in the field. They probably have a track record of membership of a number of groups, they may have a social science background, they are familiar with research evidence in patient and professional journals, they understand health care politics and they are able to abstract and generalise. Thus they develop a width of knowledge that allows them to act as a patient representative. They may be the only members of a patient group that are able to stand up effectively to the views of professionals that might otherwise prevail.

The theme of patient empowerment is developed further in a review article by Dixon-Woods.<sup>27</sup> Also of interest is an important book which was written in 1975, in an era when the patient voice was heard much less in health care politics. It describes how social structure, rather than professionals themselves may repress patient interests.<sup>28</sup> That may still be true, despite the rise of the patient movement.

## Evidence based medicine and patient choice

Evidence based medicine and patient choice are important strands of NHS policy. They come together in good quality information materials.<sup>29</sup>

Holmes-Rover et al describe 'traditional' information. This makes a recommendation about an intervention, and goes on to explain how it works, why it is good and, sometimes, what the risks are. They contrast this with a new style of information which 'offers a description of the various possible interventions (including no intervention), a comparison of their consequences (benefits and harms) and an opportunity to consider these consequences in relation to life circumstances and patient preferences'.<sup>30</sup> Thus patients are offered information about alternatives which allows them to take part in decision making.

The same authors identify the importance of wide and timely availability of this kind of information:

*'Time constraints in modern consultations necessitate that such information be widely available before, during, and after the consultation.'*<sup>30</sup>

In some areas there is considerable debate and uncertainty about the effectiveness of treatments and patients may be unaware of this.<sup>31,32</sup> Sharing this uncertainty with patients will require a major shift in perspective among patients and the public:

*'Patients and the public will: 'need to become comfortable with uncertainty and the chance of a less than perfect outcome.'*<sup>31</sup>

Many professionals express concern that pre-operative information may increase anxiety, and some evidence exists both ways on this matter.<sup>33,34,35,36</sup> These references include one on paediatric anaesthesia and one on maternity services. A Cochrane review in May 2002 reviews the literature on reducing anxiety before surgery and discusses the effect of pre-operative information on anxiety.<sup>37</sup> This useful document states that:

*'While unquestionably some information may make some people more anxious, research has shown that in general, people having surgery do not get as much information as they would like.'*<sup>37</sup>

Some information materials appear to offer a choice, but do not give all the alternatives or may be biased towards a particular option.<sup>30,38</sup> This was illustrated by Coulter and colleagues in a study of 54 patient information materials on ten common conditions.<sup>18</sup>

The need for an evidence base for clinical information may be obvious, but the need for evidence of patient concerns and priorities is less obvious and often lacking. This is a crucial gap, because the concerns of patients and health professionals may differ.

*'Patients ... have important insights and priorities that doctors and other health professionals miss.'*<sup>39</sup>

Patients and patient groups are a rich source of data on patient experiences, values and perspectives. Not all of this is published, but more and more is available on the internet. DIPEX is a leading website in this area.<sup>40</sup>

Information materials are widely available on the internet. Some recommended sites are listed here<sup>41,42,43</sup> and quality issues are discussed in a review article in the British Medical Journal.<sup>44</sup>

## Difficult issues: risk and uncertainty

*'Although physicians often describe the nature of decisions to their patients, they less often discuss risks and benefits and rarely assess patient understanding of those risks.'*<sup>45</sup>

This is likely to be related to lack of time, lack of training of the physician, and a belief that patients are not comfortable with uncertainty.<sup>31</sup> However:

*‘Pretending to know the future or exact diagnosis fools no-one and is likely to lessen satisfaction and empowerment. It is perfectly possible to acknowledge uncertainty about a diagnosis or prognosis whilst giving the patient a clear positive message about what they can expect to happen...or what to do if things do not go according to expectation.’<sup>32</sup>*

‘Quality in Health Care’ devotes a whole issue to ‘Communicating and Understanding Risk.’ One article discusses the difficulty of avoiding bias in the presentation of risk information.<sup>38</sup> It also advocates comparison with everyday risks with which the consumer is familiar. The Department of Health has issued guidance on communication about risk,<sup>46</sup> and Sir Kenneth Calman has also written on the subject.<sup>47,48</sup> A useful review article includes the use of pictorial devices to help the understanding of risk.<sup>49</sup>

The knowledge base on risk is very diffuse and crosses several disciplines including the food industry, the nuclear industry and the environment. ‘Risk, Communication and Public Health’ provides an in depth study of the issues.<sup>50</sup> The work of Frewer in the nutrition field is extremely valuable,<sup>51</sup> as is the work on the GM debate.<sup>52</sup> A discussion of risk communication in anaesthesia is also available.<sup>53,54</sup>

In the past decade both English and Australian courts have adopted a patient centred standard in deciding what risks doctors must disclose. There is a shift towards requiring the doctor to give the patient the information that reasonable patients would expect, rather than the information that reasonable doctors would provide.<sup>6,55</sup> The legal and ethical implications are far-reaching:

*‘Doctors who do not understand these changes in society and in the law are at increased risk of liability in negligence.’<sup>55</sup>*

*Errors, Medicine and the Law* is a book which has been described as ‘superb’ by a British Medical Journal reviewer.<sup>56,57</sup>

## Implementation – changes required

These papers discuss some of the barriers to the implementation of shared decision making:<sup>12,31,58,59</sup>

- Changes in physician and nurse attitudes will be needed.
- Training in communication skills and in techniques to promote shared decision making is required. Doctors and patients may talk to each other ‘using different voices’ and other cultural issues may exist within the consultation process.
- Time for discussion and a deliberative approach will be needed.
- Patients will need to gain experience in making decisions and they may need to become accustomed to uncertainty.

Some training resources are available on the internet.<sup>60</sup>

## Patient information for anaesthesia

Some specialties have well-researched and developed principles for providing information for patients – oncology for example. Applying the learning from these studies to anaesthesia is clearly in its early stages. The Patient Information Project aims to make a large step forward in this

regard. There is still a lot to be learned about the appropriateness of different approaches.

Risk, dealing with uncertainty and consent issues pose particular challenges in anaesthesia:

*‘Particular importance relates not only to the risks themselves but the belief that anaesthesia is ‘risky’.’<sup>54</sup>*

A full and helpful discussion about the science of risk perception relating in particular to anaesthesia is available.<sup>53</sup> Adverse outcomes in anaesthesia may lead to large litigation payments and anaesthetists need to take particular note of the shift in legal requirements for informed consent. The doctor must:

*‘Give the patient the information that reasonable patients would expect, not the information that reasonable doctors would provide’.<sup>55</sup>*

If this does not occur, consent may be invalid.<sup>5,6</sup>

A number of papers investigate the existing knowledge base of patients on anaesthesia.<sup>61,62,63,64</sup> One paper describes clinical anaesthesia outcomes that patients are most anxious to avoid.<sup>65</sup> Papers also describe patient priorities in anaesthesia information.<sup>64,66,67,68,69</sup> A MORI Poll was commissioned by the Royal College of Anaesthetists for National Anaesthesia Day 2001.<sup>66</sup> 1857 adults were interviewed throughout Great Britain. This poll shows that patients want to be well-informed about aspects of anaesthesia. The following areas were rated ‘important’ by patients:

- Knowing how any pain will be dealt with after surgery (93%).
- Knowing whether there is any risk of waking up or being aware during surgery (91%).
- Knowing the risk of disability and death (90%).
- Knowing that the anaesthetist will be a qualified doctor (88%).
- Meeting and talking to my anaesthetist on the ward before going to theatre (85%).
- Knowing how long I will be asleep (68%).

The effect of pre-operative information about anaesthesia on anxiety levels has been studied briefly<sup>35,36</sup> and peri-operative anxiety is discussed further in other papers including a Cochrane review.<sup>33,34,37</sup>

Patient information booklets (PILS) for individual anaesthetic drugs are provided by manufacturers as a requirement of drug licensing. The quality, value and effect on patients of these booklets is discussed.<sup>70,71,72</sup>

This resource guide concludes with a list of internet based sources of information on anaesthesia for consumers. Most originate in North America and their inclusion here is not an indication of quality. As far as we are aware, they have not been quality assured and there is no indication of how patients were involved in their development.<sup>73,74,75,76,77,78</sup>

A list of useful organisations with contact details is also given below.

## References

The notes given with each reference are the opinions of the authors of this chapter. They may be based on the authors' abstract, but abstracts are not given in full for reasons of space. Where possible Pubmed identification numbers are given.

- 1 [www.doh.gov.uk/nhsplan](http://www.doh.gov.uk/nhsplan).
- 2 [www.doh.gov.uk/coinh.htm](http://www.doh.gov.uk/coinh.htm).
- 3 [www.bristol-inquiry.org.uk/index.htm](http://www.bristol-inquiry.org.uk/index.htm).
- 4 [www.rlcinquiry.org.uk/](http://www.rlcinquiry.org.uk/).
- 5 **Reference guide to consent for examination or treatment.** Department of Health 2001: [www.doh.gov.uk/consent](http://www.doh.gov.uk/consent). This guide sets out the NHS policy on consent and gives a comprehensive summary of the law on consent. It states that patients must receive written information on treatment options, to back up a verbal discussion. If patients do not receive information on which to base their decision, then the consent may not be valid.
- 6 **Chester v Afshar (2002).** EWCA Civ 724. All England Law Reports (2002);3:552–573.
- 7 **Seeking patients' consent: the ethical considerations.** General Medical Council. London 1998.
- 8 [www.gmc-uk.org/standards/consent.htm](http://www.gmc-uk.org/standards/consent.htm).
- 9 **Shared decision making in the medical encounter: what does it mean? (or it takes at least two to tango).** Charles C, Gafni A, Whelan T. *Social Science and Medicine* 1997 44;(5):681–692. This study focuses on life-threatening illnesses, where several treatment options exist with different possible outcomes and substantial uncertainty. Four key characteristics of shared decision making are identified: (a) that at least two participants (physician and patient) be involved; (b) that both parties share information; (c) that both parties take steps to build a consensus about the preferred treatment; and (d) that an agreement is reached. The challenges and potential benefits of shared decision making are discussed. Pubmed ID: 9032835.
- 10 **Informed decision making: an annotated bibliography and systematic review.** Bekker H, Thornton JG et al. *Health Technology Assessment* 1999;3;(1). Pubmed ID: 10350446.
- 11 **Patient Participation in decision making.** Guadagnoli E, Ward P. *Social Science and Medicine* 1998 47;(3):329–339. This is a systematic review of research on patient participation in decision making. It concludes that '(a) patients want to be informed of treatment alternatives, (b) they, in general, want to be involved in treatment decisions when more than one treatment alternative exists, and (c) the benefits of participation have not yet been clearly demonstrated in research studies.' They conclude that 'patient participation in decision making is justified on humane grounds alone and that physicians should endeavour to engage patients in decision making'. Pubmed ID: 9681902.
- 12 **Framework for teaching and learning informed shared decision making.** Towle A, Godolphin W. *British Medical Journal* 1999;319:766–771. This in-depth study looks at the challenges of shared decision making. These include perceived lack of time, lack of physician predisposition and skill, and patients' inexperience with making decisions about treatment. Pubmed ID: 10488010.
- 13 **What is the scope for improving health outcomes by promoting patient involvement in decision making?** Georgiou A, Robinson M. Northern and Yorkshire R&D Portfolio Programme (Report no.4) at the Nuffield Institute for Health, December 1999 or at: [www.leeds.ac.uk/nuffield/portfolio/patient.pdf](http://www.leeds.ac.uk/nuffield/portfolio/patient.pdf). Although the evidence is still very limited, there are some indications that shared decision making can have a positive influence on patients' health. There are also considerable moral and ethical grounds for promoting greater patient participation. The authors offer practical recommendations which seek to improve the consultation process, increase patient participation in treatment decisions and improve the quality of the decisions made.
- 14 **Decision aids for patients facing health treatment or screening decisions: systematic review.** O'Connor AM et al. *British Medical Journal* 1999;319:731–734. This is a systematic review of randomised trials of patient decision aids. The authors conclude that: 'Decision aids improve knowledge, reduce decisional conflict, and stimulate patients to be more active in decision making without increasing their anxiety. Decision aids have little effect on satisfaction and a variable effect on decisions. The effects on outcomes of decisions (such as quality of life) remain uncertain.' Pubmed ID: 10487995.
- 15 **Decision aids for people facing health treatment or screening decisions (Cochrane Review).** O'Connor AM, Stacey D et al. *Cochrane Database Systematic Review* 2001;(3). This is a recent review of 87 different decision aids. Trials of decision aids indicate that they: 'improve knowledge and allow realistic expectations of the benefits and harms of options; they reduce passivity in decision making and lower decisional conflict stemming from feeling uninformed'. However, 'To date, decision aids have had little effect on anxiety or satisfaction with the decision making process or satisfaction with the decision'. PubmedID: 11686990.
- 16 **decision making in the physician-patient encounter: revisiting the shared treatment decision making model.** Charles C, Gafni A, Whelan T. *Social Science Medicine* 1999;49(5):651–661. Pubmed ID: 10452420.
- 17 **Supporting and resourcing treatment decision making: some policy considerations.** Entwistle VA. *Health Expectations* 2000;3(1):77. This author argues that: 'Policies of informing people and involving them in decisions about their care are unlikely to be simple to implement. Various strategies might be needed to support them. These include the development of appropriate skills among health professionals and in the general population, the use of interventions to encourage people to play more active roles in decisions about their health care, the provision of decision aids for people facing specific decisions and the provision and accreditation of more general information resources and services.' Pubmed ID: 11281914.
- 18 **Sharing decisions with patients: is the information good enough?** Coulter A, Entwistle V, Gilbert D. *British Medical Journal* 1999;318:318–322. This is a study of 54 information booklets on ten common conditions. The authors state that: 'Current information materials for patients omit relevant data, fail to give a balanced view of the effectiveness of different treatments, and ignore uncertainties.' They conclude that: 'Groups producing information materials must start with needs defined by patients, give treatment information based on rigorous systematic reviews, and involve multidisciplinary teams, including patients, in developing and testing the materials.' Pubmed ID: 9924064. ALSO see: *Informing patients: An assessment of the quality of patient information materials.* Coulter A, Entwistle V, Gilbert. D Kings Fund Publishing, London 1998.
- 19 **Practicalities of producing patient information: the POPPi Guide.** Duman M, Farrell C. King's Fund Publications 2000. This guide was produced as part of the project 'Promoting Patient Choice'. It sets out criteria for good quality patient information. It is a valuable and practical resource for anyone producing health information materials.
- 20 **How to Write Medical Information in Plain English.** Plain English Campaign 2001: [www.plainenglish.co.uk](http://www.plainenglish.co.uk). This is essential reading for anyone writing information for patients. It is full of tips about how the plain English approach can make medical information more clear. It contains a glossary of technical terms translated into plain English.
- 21 **Centre for Health Information Quality, ChiQ:** [www.hfht.org/chiq/index.htm](http://www.hfht.org/chiq/index.htm). The philosophy of this organisation is that: 'good quality patient information is evidence-based, clearly communicated and involves patients throughout production.' Individuals with appropriate training in information appraisal can offer advice and an evaluation service to anyone writing patient information materials.

- 22 **DISCERN project:** www.discern.org.uk. DISCERN is run by the Department of Public Health and Primary Care at the University of Oxford. The DISCERN model is a questionnaire which provides users with a valid and reliable way of assessing the quality of health information materials. Criteria include: Is the publication reliable (up to date, evidence-based)? How good is the quality of information on treatment choices? Does it include information on risks and benefits and on the consequence of no treatment? Is there support for shared decision making? Is the impact on quality of life discussed? See also: Charnock D. The DISCERN Handbook. Quality Criteria for Consumer Health Information on Treatment Choices. Oxford: Radcliffe Medical Press, 1998.
- 23 **Evaluation of the quality of patient information to support informed shared decision making.** Godolphin W, Towle A, McKendry R. Health Expectations 2001;4(4):235. All printed information given to patients on a single day of the office practices of 21 family physicians was collected. A published and validated instrument (DISCERN) was used to assess quality. The authors found that: ‘the quality of patient information materials ... was below midpoint on the DISCERN score. ‘Major deficiencies were the mention of choices, risks, uncertainties, the effect of no treatment, and inclusion of a source for the information. Pubmed ID : 11703497.
- 24 **Recordings or summaries of consultations for people with cancer (Cochrane Review).** Scott JT, Entwistle VA, Sowden AJ, Watt I. The Cochrane Library, 1, Oxford 2002. This review examined the effects of providing recordings or summaries of their consultations for people with cancer and their families. The conclusions were that: ‘Although more research is needed to improve our understanding of these interventions, most patients find them very useful.’ Pubmed ID: 10796807.
- 25 **Consumer and Professional standards: working towards consensus.** Williamson C. Quality in Health Care 2000;9:190–194. This paper discusses the role of professional/consumer groups in setting standards of care that are acceptable to healthcare consumers as well as to professionals. Pubmed ID: 10980080.
- 26 **The rise of doctor patient working groups.** Williamson C. British Medical Journal 1998;317:1374–1377. Pubmed ID: 9812941.
- 27 **Writing wrongs? An analysis of published discourses about the use of patient information booklets.** Dixon-Woods M. Social Science and Medicine 2001;52(9):1417–1432. This paper looks at publications on the use of patient information booklets. It suggests that two discourses can be distinguished in this literature. The first of these is the larger of the two. It reflects traditional biomedical communication and patient ‘education’ in which patients are characterised as passive and open to manipulation. The second discourse is more recent in origin and draws on a political agenda of patient empowerment. It involves describing outcomes which are of interest to patients, the use of booklets as a means of democratisation and it is oriented towards patients. Pubmed ID: 11286365.
- 28 **Health care politics, ideological and interest group barriers to reform.** Alford RR. Chicago: University of Chicago Press 1975.
- 29 **Evidence-based Patient Choice.** Hope T. King’s Fund, London 1996. This report explores the concepts of evidence-based medicine, patient choice, and the relationship between them. There is an overview of ways in which information can be given to patients to promote informed choice. A framework for appraising evidence-based patient choice is suggested. There is an extensive bibliography.
- 30 **Patient choice modules for summaries of clinical effectiveness: a proposal.** Holmes-Rovner M, Llewellyn-Thomas H, Entwistle V, Coulter A, O’Connor A, Rovner DR. British Medical Journal 2001;322:664–667. The need for evidence based information to support patient choice is described and the importance of making this information available before (and after) any consultation is emphasized. The value of decision aids is discussed. Patient choice modules should form a part of key assessments of health care quality. Pubmed ID: 1250855.
- 31 **Implementing shared decision making in routine practice: barriers and opportunities.** Holmes-Rovner M, Valade D, Orłowski C, Draus C, Nabozny-Valerio B, Keiser S. Health Expectations 2000;3(3):182. This study looks at the feasibility of introducing shared decision making into a fee-for-service US hospital. The authors argue that: ‘If partnership is to replace paternalism in medical decision making, two things have to change even beyond a change in physician and nurse attitudes. One is that time and a deliberative approach must replace the rush and drama of treatment decision making. The second is that patients must become comfortable with uncertainty and the chance of less than perfect outcomes. Both are large changes’. Pubmed ID: 11281928.
- 32 **Airing uncertainty can be positive (letter).** Shepherd D. British Medical Journal 2001. Dr David Shepherd is a GP Principal and GP Trainer. Helping patients deal with uncertainty is an important part of doctor patient relationships. It is likely to be perceived as positive by the patient who may feel even more empowered as the doctor has clearly planned for the uncertainty that all patients know exists.
- 33 **The effects of giving patients pre-operative information.** Hughes S. Nursing Standard 2002;16(28):33–37. This is a literature review of the evidence that pre-operative information reduces anxiety levels. Pubmed ID: 11949188.
- 34 **Use of evidence based booklets to promote informed choice in maternity care: randomised controlled trial in everyday practice.** O’Cathain A et al. British Medical Journal 2002;324:643. This trial compared maternity units which were asked to give a written information leaflet on informed choice to their ante natal women with maternity units who offered ‘usual care’. Pubmed ID: 11895822.
- 35 **The introduction of a paediatric anaesthesia information leaflet; an audit of its impact on parental anxiety and satisfaction.** Bellew M et al. Paediatric Anaesthesia 2002;12:107–109. This audit showed that the leaflet used was accessible, informative and useful and those who received it reported greater satisfaction with information provision than a control group. Pubmed ID: 11882223.
- 36 **Do patient information booklets increase peri-operative anxiety?** Gillies MA. European Journal of Anaesthesiology 2001;18:620–622. This is a survey of 103 patients who received a booklet about anaesthesia pre-operatively. 99% patients said that they found it helpful, but 35% said that it worried them and only 3% discussed these fears with the anaesthetist. PubmedID: 11553258.
- 37 **Reducing anxiety before surgery.** Hot Topic of the month (May 2002): www.cochraneconsumer.com. This review article describes causes of anxiety before surgery and outlines strategies for reducing anxiety. This includes a section on the provision of information. Self help, play therapy and story telling for children and the use of drugs to reduce anxiety, including herbal medicines are described.
- 38 **Understanding risk and lessons for clinical risk communication about treatment preferences.** Edwards A, Elwyn G. Quality in Health Care 2001;10(suppl 1):i9–13. The authors give some practical and cautionary examples of the risk of bias and ‘framing’ manipulations. They argue that information should be presented (framed) in a fair and balanced way, and they advocate the comparison with everyday risks with which the consumer is familiar. Training programmes should address these issues. Pubmed ID: 11533431.
- 39 **Enriching the doctor patient relationship by inviting the patient’s perspective.** Delbanco TL. Annals of Internal Medicine 1992;116:414–418. This author describes an explicit strategy for ensuring that the values and preferences of patients are incorporated into the clinical encounter. Seven ‘dimensions of care’ are identified for review. These include respect for patient’s values, communication and education, physical comfort, emotional support, alleviation of anxiety and involvement of family and friends. Pubmed ID: 1736775.

- 40 **DIPEX: database of patient experiences of illness.** Herxheimer A, McPherson A. [www.dipex.org](http://www.dipex.org). DIPEX is a registered charity based in Oxford University's Department of Primary Care. It was founded by the former editor of the Drug and Therapeutics Bulletin and a GP who was diagnosed with breast cancer five years ago. The site answers questions about what a diagnosis means and what the person should do about it. It also has video clips of people relating their experiences of illness and the impact it has had on their lives. These are intended not just for those with the illness but also for their families and carers and health professionals, and for teaching medical students.
- 41 **Cochrane Consumer Network:** [www.cochraneconsumer.com](http://www.cochraneconsumer.com). This site contains a range of health care information, articles and 'teach yourself' resources. There are summaries of Cochrane reviews of both conventional and complementary therapies. Health systems and policy issues are discussed.
- 42 **Bandolier** [www.jr2.ox.ac.uk/bandolier/](http://www.jr2.ox.ac.uk/bandolier/). This print and internet health care journal uses evidence-based medicine techniques to provide advice about particular treatments or diseases for healthcare professionals and consumers. Each month Pubmed and the Cochrane Library are searched for systematic reviews and meta-analyses.
- 43 **HEBS Consulting Room:** [www.hebs.scot.nhs.uk/healthcentre/consult/consult.htm](http://www.hebs.scot.nhs.uk/healthcentre/consult/consult.htm). This excellent resource is provided by the Health Education Board for Scotland. It gives information for professionals or patients about specific diseases or illnesses, guidelines for the management of conditions and reference publications. Also available is the full text of many HEBS booklets and the Support Groups database.
- 44 **Helping patients access high quality health information.** Shepperd S, Charnock D, Gann R. *British Medical Journal* 1999;319:764–766. This review article gives examples of widely used gateway sites that use approved guidelines for selecting information. The references give reviews of well known websites that provide public access to health information. Pubmed ID: 10488009.
- 45 **A key medical decision maker: the patient (editorial).** Deyo R. *British Medical Journal* 2001;323:466–467. The author states that risk/benefit information is not always given to patients. Informed consent 'usually takes the form of seeking patient agreement with a recommendation, rather than quantifying the risks and benefits of alternative approaches.' He argues the need to use a new generation of decision aids which make choices explicit, rather than implying a preferred course. Pubmed ID: 11532825.
- 46 **Communicating about risks to public health: pointers to good practice.** London: Department of Health, 2001 or at [www.doh.gov.uk/pub/docs/doh/pointers.pdf](http://www.doh.gov.uk/pub/docs/doh/pointers.pdf).
- 47 **Risk language and dialects.** Calman KC, Royston HD. *British Medical Journal* 1997;315:939–942. Pubmed ID: 9361547.
- 48 **Communication of risk: choice consent, trust.** Calman KC. *Lancet* 2002;360:166–168. Pubmed ID: 12126841.
- 49 **Explaining risks: turning numerical data into meaningful pictures.** Edwards A, Elwyn G, Mulley A. *British Medical Journal* 2002;324:827–830. Pubmed ID: 11934777.
- 50 **Risk, Communication and Public Health.** Bennett P, Calman K, eds. Oxford: Oxford University Press, 1999:20–32.
- 51 **Risk perception and risk communication about food safety issues.** Frewer L. *Nutrition Bulletin* 2000;25(1):31. This paper discusses the psychological factors that influence public perceptions of risk. There are likely to be large differences in peoples beliefs and information needs. These should be understood and information targeted to suit different information requirements.
- 52 **The politics of GM food: Risk, science and public trust.** ESRC Global Environmental Change Programme Special Briefing No.5, October 1999.
- 53 **Risk perception and communication: recent developments and implications for anaesthesia.** Adams AM, Smith AF. *Anaesthesia* 2001;56(8):745–755. This review outlines the history of probability theory, and exposes cultural differences between scientists and lay people in the way risks are viewed. It describes the basic principles of the science of risk perception and the methods of communicating risk in health care, including numerical and descriptive terms. These concepts are applied to the practice of anaesthesia, including possibilities for training in risk perception issues. The authors argue that: 'the main purposes of conveying risk information are to allow informed decision making and ... to limit individual exposure to adverse events ...'. Pubmed ID: 11493237.
- 54 **Risk Perception and Communication: Informed Consent (letter).** Lake AJ. *Anaesthesia* 2001 Dec;56(12):1204. Pubmed ID: 11766675. This reply to the previous article stresses the need to 'formally define and list the procedural risks that are appropriate to be communicated to the patient under varying circumstances during the process of obtaining informed consent.'
- 55 **Informed consent: lessons from Australia.** Skene L, Smallwood R. *British Medical Journal* 2002;324:39–41. Courts in Australia and England have begun to apply a tougher standard to the information that doctors should give their patients – 'that of what a reasonable patient might expect rather than of what a reasonable body of doctors might think.' They outline some recent cases in Australia and argue that: 'doctors have not yet caught up with this change in judges' thinking and are thus laying themselves open to negligence claims.' Pubmed ID: 11777808.
- 56 **Errors, Medicine and the Law.** Merry A, McCall Smith A. Cambridge University Press. ISBN: 0 521 00088 2. Merry is a cardiac anaesthetist from New Zealand and McCall Smith is professor of medical law in Edinburgh. A *British Medical Journal* reviewer (57) recommends this as: 'a superb book'. It discusses the relation between blame and fault and the difference between errors and violations. Reading the book requires concentration, especially in the middle chapters about negligence and the standard of care, but the writing is clear and logical. They are not kind to expert witnesses. They finish by considering how we might change or abandon our tort based system.
- 57 **Review of 'Errors, Medicine and the Law'.** Goodman NW. *British Medical Journal* 2002;324:304.
- 58 **Engaging patients in medical decision making (Editorial).** Kravitz RL, Melnikow J. *British Medical Journal* 2001;323:584–585. Collaborative decision may be achievable in a research setting but it is not realistic in a 15 minute visit to a general practitioner or even a 45 minute consultation with a specialist. We need training in practical tools, based on research, that will help clinicians to learn from patients and help patients learn from medical experts. Pubmed ID: 11557690.
- 59 **Engaging patients in decisions: a challenge to health care delivery and public health.** Thomson R, Bowling A, Moss F. *Quality in Health Care* 2001;10: suppl 1–i1. These papers consider how patient preferences can be genuinely incorporated into routine practice. They were prepared for a workshop sponsored by the MRC Health Services Research Collaboration (HSRC) which brought together key researchers from across the UK. The authors argue that although few would disagree with the principle of engaging patients in decision making, the changes needed in clinical practice and delivery of health care that will move policy from lip service to a reality have yet to be made. Pubmed ID: 11533429.

- 60 **WISDOM:** [www.wisdomnet.co.uk](http://www.wisdomnet.co.uk). This is a networked professional development programme for primary care using internet technology hosted by the NHS Executive Trent. It provides a: 'virtual classroom', including electronic discussion groups, learning materials, virtual seminars and links to libraries and resources. They recently hosted a workshop on public involvement. There are two keynote articles by Dr Alan O'Rourke from the University of Sheffield on 'Public Involvement: threat or opportunity?' and on 'Patient Satisfaction.' Both have a useful reference section.
- 61 **Patient knowledge of anaesthesia and peri-operative care.** Hume MA, Kennedy B, Asbury AJ. *Anaesthesia* 1994;49(8):715–718. This is a survey of knowledge about anaesthesia in 166 patients. Important misconceptions were identified: 28% of respondents thought that fasting referred to food only, and not to fluid intake. 48% of respondents considered pain to be a necessary part of the healing process and 39% believed that it was something that just had to be endured. Anaesthetists need to be sure that patients understand the language used in pre-operative discussions. Pubmed ID: 7943707.
- 62 **Patients' Knowledge of Perioperative Care.** Laffey JG, Coleman M, Boylan JF. *Ir Journal of Med Science* 2000;169(2):113–118. This study investigated patients' knowledge of anaesthesia, surgery and pain control. 300 patients were surveyed on three occasions: before a routine pre-anaesthetic visit, two to three hours after this visit and on the day of discharge from hospital. Knowledge at all stages was limited and there was little change following either the pre-anaesthetic visit or postoperative convalescence. Male patients, older patients and patients in lower socio-economic groups had poorer knowledge. Novel educational approaches may be required to increase basic medical knowledge. Pubmed ID: 11006666.
- 63 **Patients' knowledge of anaesthesia.** Lipp A. *Anaesthesia* 1994;49(12):1104. Pubmed ID: 7864347.
- 64 **Patient's pre-operative knowledge and concerns about anaesthesia.** Eckersall S, Riley R. *Anaesthesia* 1995;50(2):180. Pubmed ID: 7710039.
- 65 **Which clinical anesthesia outcomes are important to avoid? The perspective of patients.** Macario et al. *Anesthesia and Analgesia* 1999;89:652–658. This study asked 100 patients to rank ten possible adverse outcomes in anaesthesia. They were also asked to spend an imaginary \$100 on preventing the ten outcomes and the distribution of money spent on each outcome was examined. The outcomes the patients most wanted to avoid were vomiting, gagging on the endotracheal tube, pain and recall. Pubmed ID: 10475299.
- 66 **MORI Poll for National Anaesthesia Day 2001.** Perceptions of Anaesthetists – A survey of the general public. Research study conducted for The Royal College of Anaesthetists for National Anaesthesia Day 2001. Market and Opinion Research International, London.
- 67 **Anaesthesia information – what patients want to know.** Garden AL, Merry AF, Holland RL, Petrie KJ. *Anaesthesia and Intensive Care* 1996;24(5):594–598. The amount of information given prior to gaining consent for anaesthesia should be 'what the reasonable patient thinks is appropriate'. This study compared three levels of information: 'full', 'standard' and 'minimal'. 45 patients scheduled to undergo cardiac surgery took part in the study. None of the information sheets caused a significant change in anxiety score and only the 'full' disclosure significantly increased knowledge. When only one leaflet was provided, 64–73% patients thought the information was 'just right', but when patients saw all three booklets, 63% thought that the 'minimal' leaflet withheld too much information. Pubmed ID: 8909673.
- 68 **Information and anaesthesia: what does the patient desire?** (French). Asehnoune K et al. *Ann Fr Anesth Reanim* 2000;19(8):577–581. This study compares patient and anaesthetist ranking of information needs. Patients sought information most frequently about postoperative pain and postoperative recovery (88%), time to ambulation (83%), duration of anaesthesia (77%) and different methods of anaesthesia (77%). Only 63% patients wanted information about all possible complications of anaesthesia. Senior anaesthetists correctly predicted the first four topics, but placed information about complications at a higher level. The authors suggest that not every patient wants exhaustive information about complications of anaesthesia. Pubmed ID: 11098318.
- 69 **Preoperative anaesthesia information – what do patients need to know?** Lennox P, Cunningham AJ. *Irish Journal of Medical Science* 2000;169(2):93–95. Pubmed ID: 11006660.
- 70 **Anaesthetic drug information booklets – for the patient or for the doctor?** Bamgbade O. *Anaesthesia* 2001;56(12):1203. PubmedID: 11766682.
- 71 **Drug patient information booklets.** Brookes AJ. *Anaesthesia* 2001;56(2):195. Pubmed ID: 11167505.
- 72 **Patient information booklets for anaesthetic drugs.** Paoloni CC, Arrowsmith JE. *Anaesthesia* 2000 Sep;55(9):911. Pubmed ID: 10991752.
- 73 **'Anaesthesia and You':** [www.cas.ca/anaesthesia/](http://www.cas.ca/anaesthesia/). The Canadian Anaesthesiologists' Society website. This includes frequently asked questions, and a patient information brochure which can be printed out.
- 74 **American Society of Anesthesiologists:** [www.asahq.org/PublicEducation/homepage.html](http://www.asahq.org/PublicEducation/homepage.html). This is a large website with extensive resources for patient information.
- 75 **A patient's guide to local and regional anaesthesia:** [www.oyston.com/anaes/local.html](http://www.oyston.com/anaes/local.html). Dr J Oyston. This website is produced by an anaesthetist working in Ontario, Canada. It has several useful links.
- 76 **The Virtual Hospital – Anesthesia:** [www.vh.org/Providers/ProviderDept/InfoByDept.Anes.html](http://www.vh.org/Providers/ProviderDept/InfoByDept.Anes.html). The University of Iowa Virtual Hospital is a digital health sciences library created in 1992. It contains extensive reference materials and brochures for health care providers and patients.
- 77 **Anesthesia.Net:** [www.anesthesia.net/](http://www.anesthesia.net/). This is an interactive website dedicated to helping the patient who is preparing for surgery understand the experience of anesthesia. It is run by Valley Anesthesiology Consultants, a large group of Anesthesiologists in Phoenix, Arizona.
- 78 **Everything you never wanted to know about anesthesia!** [www.choosegha.com/afraid.htm](http://www.choosegha.com/afraid.htm). This website was developed in Houston, Texas. There are several patient related sections including feedback.

# Useful organisations

## Patient and public information and involvement

### Centre for Health Information Quality

The Help for Health Trust, Highcroft, Romsey Road, Winchester SO22 5DH **tel** 01962 872264 **fax** 01962 849079

**email** [chiq@hfht.org](mailto:chiq@hfht.org) **website** [www.chiq.org](http://www.chiq.org)

The Centre for Health Information Quality works directly with the NHS and patient representative groups to raise awareness of key issues in the development of consumer health information.

### Consumers in NHS Research

Support Unit, Wessex House, Upper Market Street, Eastleigh, Hampshire SO50 9FD **tel** 023 8065 1088

**email** [admin@conres.co.uk](mailto:admin@conres.co.uk) **website** [www.conres.co.uk](http://www.conres.co.uk)

This unit will soon be able to provide advice and support to researchers on how to involve consumers in their work, and to consumers who want to be involved in NHS research.

### DISCERN Online

c/o Radcliffe Medical Press Ltd, 18 Marcham Road, Abingdon, Oxford OX14 1AA **tel** 01235 528820 **fax** 01235 528830

**email** [medical@radpress.win-uk.net](mailto:medical@radpress.win-uk.net) **website** [www.discern.org.uk](http://www.discern.org.uk)

The DISCERN handbook: quality criteria and checklist for consumer health information on treatment choices.

### The Guild of Health Writers

1 Broadmead Close, Hampton, Middlesex TW12 3RT

**tel/fax** 020 8941 2977 **email** [admin@healthwriters.com](mailto:admin@healthwriters.com)

**website** [www.healthwriters.com](http://www.healthwriters.com)

A group of authors and journalists, which covers the whole spectrum of health and wellbeing. The Guild publishes a clear directory of its membership with contact details, areas of interest and affiliations. Membership includes some of Britain's best-known health columnists, freelance writers, broadcasters and authors.

### Medical Journalists Association

**website** [www.medicaljournalists.org.uk/](http://www.medicaljournalists.org.uk/)

### NHS Direct

**tel** 0845 4647 **website** [www.nhsdirect.nhs.uk/](http://www.nhsdirect.nhs.uk/)

This is a 24 hour telephone information service for the public which can provide advice on acute and chronic illness.

### Plain English Campaign

PO Box 3, New Mills, High Peak, SK22 4QP **tel** 01663 744409

**fax** 01663 747038 **email** [info@plainenglish.co.uk](mailto:info@plainenglish.co.uk)

**website** [www.plainenglishcampaign.com](http://www.plainenglishcampaign.com)

The Plain English Campaign encourages organisations to communicate clearly with the public. They run training courses, offer advice on clear communication and can provide comments on draft materials. They award a Plain English Crystal Mark for materials that present information clearly.

## Patient information Forum

28 Queensbury Street, London N1 3AD **tel** 020 7688 9208

This organisation holds meetings and publishes a newsletter about information for patients in all areas of health care. The newsletter includes a useful list of all recent publications on patient information that are published in peer reviewed journals and elsewhere.

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## Sources of information about systematic reviews and other reliable research evidence

### Cochrane Database of Systematic Reviews

available on CD-ROM and via

**website** [www.hiru.mcmaster.ca/cochrane/cochrane/cdsr.htm](http://www.hiru.mcmaster.ca/cochrane/cochrane/cdsr.htm)

This includes the full texts of systematic reviews prepared by the Cochrane Collaboration. It also includes the NHS Centre for Reviews and Dissemination Database of Abstracts of Reviews of Effectiveness (DARE), which contains summaries of systematic reviews that have passed a minimum quality threshold.

### National Blood Service

Colindale Ave, London NW9 5BG **tel** 0845 7711711

**website** [www.blood.co.uk](http://www.blood.co.uk)

A part of the NHS, and guarantees to deliver blood, blood components, blood products and tissues from blood centres to anywhere in England and North Wales.

### National Confidential Enquiry into Perioperative Deaths (NCEPOD)

35–43 Lincoln's Inn Fields, London WC2A 3PE **tel** 020 7831 6430

**fax** 020 7430 2958 **email** [info@ncepod.org.uk](mailto:info@ncepod.org.uk)

**website** [www.ncepod.org.uk](http://www.ncepod.org.uk)

This is an organisation producing yearly reports on deaths following surgery. Its aim is to review clinical practice and identify areas where improvement can be made in the practice of anaesthesia, surgery and other invasive medical procedures.

### NHS Centre for Reviews and Dissemination

University of York, York YO10 5DD **tel** 01904 434555 **fax** 01904 433661

**email** [revdis@york.ac.uk](mailto:revdis@york.ac.uk) **website** [www.york.ac.uk/inst/crd](http://www.york.ac.uk/inst/crd)

The NHS Centre for Reviews and Dissemination (CRD) offers an enquiry service for information about systematic reviews and economic evaluations of health care interventions.

### UK Cochrane Centre

Summertown Pavilion, Middle Way, Oxford OX2 7LG **tel** 01865 516300

**fax** 01865 516311 **email** [general@cochrane.co.uk](mailto:general@cochrane.co.uk)

**website** [www.cochrane.org](http://www.cochrane.org)

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## Patient organisations

### The Patients Association

PO Box 935, Harrow, Middlesex HA1 3YJ **tel** 020 8423 9111

**fax** 020 8423 9119 **email** [mailbox@patients-association.com](mailto:mailbox@patients-association.com)

**website** [www.patients-association.com](http://www.patients-association.com)

This organisation provides a helpline, an information and advisory service and publications. It campaigns for a better health care service for patients.

### **Patient Concern**

PO Box 23732, London SW5 9FY

**tel/fax** 020 7373 0794 **email** patientconcern@hotmail.com

**website** www.patientconcern.org.uk

This organisation provides a helpline, information and advisory service and publication on consent-related issues. It campaigns for patient choice and empowerment.

### **Royal National Institute for the Blind (RNIB)**

RNIB Customer Services, PO Box 173, Peterborough PE2 6WS

**tel** 0845 702 3153 **fax** 01733-3715 55 **email** CServices@mib.org.uk

**website** www.rnib.org.uk

This organisation can provide assistance in the development of information materials for those with visual impairment.

### **MIDRIS (Midwives Information and Resource service)**

9 Elmdale Road, Clifton, Bristol BS8 1SL

**tel** 0800 581 009 **fax** 0117 925 1792 **email** sales@midirs.org

**website** www.midirs.org

This organisation publishes a series of booklets 'Informed Choice' which includes a leaflet on 'Epidural Pain Relief' which was highly rated by our evaluation team.

### **Scriptographic**

Scriptographic Publications Ltd, Channing House, Butts Road, Alton,

Hampshire GU34 1ND **tel** 0800 028 5670 **fax** 01420 541 743

**email** sales@scriptographic.co.uk **website** www.scriptographic.co.uk/

This organisation publishes public information on a wide range of topics including anaesthesia and going home from hospital. The publications all have the Plain English crystal mark and are highly illustrated.

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**This is a list of other information producers that have some material relating to anaesthetics. The list is not exhaustive and mention below should not be taken as any form of endorsement by the Royal College of Anaesthetists or Association of Anaesthetists of Great Britain and Ireland.**

## **Commercial and voluntary sector producers of information for patients**

### **Action for Sick Children**

c/o National Children's Bureau, 8 Wakley Street, London EC1V 7QE

**tel** 020 7843 6444 **website** www.actionforsickchildren.org

This charity produces various information booklets including a leaflet called: 'How to help children cope with pain'

### **British Malignant Hyperthermia Association (BHMA)**

11 Gorse Close, Newthorpe, Nottingham NG16 2BZ **tel** 01159 691169 ext 45293 (daytime) **tel** 01773 717901 (evening)

**email** bmha-helpline@lineone.net **website** www.bmha.co.uk

BHMA provides Medical Emergency discs and warning cards for those susceptible and family members. It publishes a newsletter and information with medical updates with regard to safe drugs, screening procedures and research. It has close links with the MH Investigation Unit in Leeds. It also offers medical and medico-social support to affected individuals and families.

### **EIDO Healthcare Ltd**

**tel** 0115 878 1000 **fax** 0115 878 9053

**email** adrian.lead@eidohealthcare.com **website** www.eidohealthcare.com

INFOrm4U library of informed consent support documents. These are written by clinicians and customisable to a Hospital's particular requirements. This series contain a number of information sheets about anaesthesia.

### **John Wiley & Sons Ltd producers of PatientWise**

**website** www.wileyurope.com/

This organisation provides information materials in many areas of health-care. There are both software and hard copy options.

# The CD – what you need to know

- To encourage the use of the booklets the CD contains a range of different file formats and all the artwork.
- The Royal College of Anaesthetists (RCA) and The Association of Anaesthetists of Great Britain and Ireland (AAGBI) agree to the copying of these files for the purpose of producing local leaflets in the United Kingdom and Ireland.
- Please quote where you have taken the information from.
- Hospital names, Trust names, contact detail and the NHS logo can be added in the space provided.
- The Patient Information Unit must agree to any other changes if the AAGBI and RCA crests are to be kept.
- The Plain English Crystal Mark on ‘*Anaesthesia explained*’ may not be retained if the document is modified without their approval. Modifications to the text should also be submitted to the Patient Information Unit.
- Check on the website for more information ([www.youranaesthetic.info](http://www.youranaesthetic.info))



The Patient Information Unit,  
48 Russell Square,  
London WC1B 4JY

**email** [admin@youranaesthetic.info](mailto:admin@youranaesthetic.info)

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## **Tell us what you think**

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Any comments or queries about this document should be directed to:

The Patient Information Unit,  
48 Russell Square,  
London WC1B 4JY  
email [admin@youranaesthetic.info](mailto:admin@youranaesthetic.info)

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The Royal College of  
Anaesthetists



The Association of  
Anaesthetists of Great  
Britain and Ireland