

Section 1

Key issues in developing new materials



The practicalities of developing patient information

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Introduction

'Information for consumers should be as rigorously prepared, as evidence – based and as broad-ranging as information for health professionals. It is demeaning to consumers to consider there is information that professionals need that consumers do not.'

National Health and Medical Research Council, Australia¹

We should like to offer ideas and information that may be helpful to those working at hospital level on patient information issues, by:

- Highlighting the reasons for the particular significance of patient information for the specialty of anaesthesia.
- Summarising the key issues we identified in our investigation of a number of available publications which give guidance on good practice in the development and production of patient information materials.
- Providing detailed practical advice on the development process for effective patient information materials, based on our own experiences and those of others.

The Patient Information Project, has been central to the development of our experience and understanding of the issues presented in this chapter. Our focus has been on written information only, not the wider questions of information policies or use of other media, and throughout we have been concerned to learn from, and build upon, established good practice. We believe that, whatever the media used, the basic principles of effective information design will still apply.

The project was underpinned by the results of a detailed survey of all UK anaesthetic departments, completed in 2001.² A majority of respondents had produced patient information materials for planned surgical admission, mainly on general anaesthesia, regional analgesia and pain relief. However, during the development of these materials, few had sought feedback from patients or used existing sources of guidance.

A four-to-one majority of respondents favoured the idea of a central resource.

The significance of patient information for the specialty of anaesthesia

When producing information for patients, we would argue that anaesthesia differs from other medical specialties in the ways listed below:

Interdependence with surgery

Limited opportunities for patients to receive information

Patient choice

Patients' perceptions of risk

No patient organisation

Department of Health policy

Interdependence with surgery

Anaesthesia is not usually a treatment in itself but is a way of achieving another treatment, usually a surgical procedure. It is therefore difficult to provide information on the risks and benefits of anaesthesia itself, since the risks and benefits of anaesthesia have to be considered alongside the risks and benefits of the procedure.

Limited opportunities for patients to receive information

When a patient agrees to surgery, for example in the out patient clinic, this is usually on the basis of information received from a surgeon about the intended procedure. Since the surgeon may not offer information about the anaesthetic technique, nor about the risks of anaesthesia, the patient generally agrees in principle to a procedure knowing very little about the anaesthetic that will be involved. Ideally there will be a pre-assessment by the anaesthetist prior to admission, and provision of written information about anaesthesia. In practice, the patient may meet their anaesthetist much later, perhaps only a short time before the procedure begins.

Patient choice

It is widely believed that patient choice in anaesthesia is very restricted. However, this view may have been overemphasised as there are areas within anaesthesia where patients can be offered choice.

Patients' perceptions of risk

Many patients regard anaesthesia as intrinsically 'risky' and fear of anaesthesia is common. Information materials need to recognise the generally safe practice of anaesthesia and to acknowledge the rare but possibly serious complications that may occur. Providing truthful, balanced information on safety and risk is a difficult area, in part because opinions and values vary greatly from person to person (see Risk Communication, Section 3).

No patient organisation

Unlike other medical specialties, there are no organisations devoted to representing the interests of patients having anaesthesia.

Department of Health policy

The Department of Health's Consent Initiative³ places the responsibility on hospitals in England to provide information for patients about general anaesthesia.

Our conclusion from this is that provision of information materials for patients about their anaesthetic treatment is at least as important as in other medical specialties.

Guidance on good practice

'... so much patient information is produced by amateur communicators, breaking many of the guidelines long since accepted by professionals.'

Tim Albert⁴

Having referred to a number of publications^{1,4-13} offering guidance on the development and production of patient information materials, we would like to emphasise two main areas: how patients should benefit from effective patient information and the basic principles that those developing information materials should observe.

Patient benefits

- Understanding their situation and the type of treatment and care they may have.
- Knowing what choices they have or could have – including the choice of refusal.
- Having a sense of control in terms of knowing what will happen and what they will feel with the various choices and treatments.
- Knowing the probability of the main and additional benefits of particular courses of action or clinical choices.
- Knowing the probability of side effects and complications, including what can be done about these.
- Knowing about the standards of care they should expect.
- Having access to definitions of technical terms, expressed in simple language, so they can: (i) use them accurately in discussions with clinicians, (ii) formulate the questions they wish to ask, (iii) ask for, or look for, further information easily, before and after their experience.
- Linking the new information that they receive to that from 'ordinary' life and past experience.

Principles to observe

- Write honestly, accurately, comprehensively and clearly with no false reassurance about competence or outcomes.
- Base what is written on evidence, providing references to evidence and further information.
- Develop the materials in partnership with patients and patient representatives throughout the process.
- Ensure materials reach patients in good time.
- Present material in such a way that it can easily be translated and put into different formats for different groups of people.
- Be honest about options that may be available in some hospitals and not in others.
- Avoid bossy or 'talking down' statements such as 'this is difficult' or 'you can't understand'.
- Ensure that the level of detail is suited to the audience and that simplification is not at the expense of accuracy. More than one version may be needed to ensure wide readership.
- Check for available guidelines for specific audiences.⁵
- Review and update regularly, by an appropriate group, including feedback from all parties.

The development process

1 Planning and preparation

Key questions at the outset:

- Who is the information for?
- Does a suitable information package already exist?
- If not, what do you want to achieve?
- Do you have the necessary skills and resources?
- How is it going to be funded?
- Who is going to be involved? (see Involving people in partnership below).
- How and when will people get copies when completed?

1.1 Search out and collect as much existing information as possible

Search broadly for information on your subject. Assess available evidence: has there been a recent review on your subject or will you need to commission one or conduct it yourself? Gather existing information materials and look at their style, design and tone. You will be able to use these as samples when your team first meets.

1.2 Check up on policy, politics and legal issues

Find out if your hospital:

- has any official patient information expertise, guidelines, policies or an authorisation committee
- takes a particular standpoint on commercial sponsorship
- requires ethics committee approval to involve patients in patient information
- will require certain things to be included, or adhered to, in your intended materials, to comply with local policies on equal opportunity issues such as the Disability Discrimination Act¹³ and the Data Protection Act.

1.3 Predict demand and confirm your budget

How many booklets will you need per year? Try and identify the potential demand. This will affect your budget, the development and production processes.

In some hospitals large numbers of booklets on anaesthesia are likely to be needed (in excess of 20,000). These will need external printing and the preparation of print files should be allowed for. Special booklets requiring short print runs (under 100) may be more economical to print or copy in house, but you may still need to allow for the cost of external editorial support.

Identify the necessary budget and confirm that you have it. Be realistic. Hospitals vary in how they budget for patient information. Some have a central printing budget for information that crosses a number of clinical departments. There may be an effective publications department with a range of services; or there may be the offer of secretarial support, Plain English training or editing skills.

Practical tips

- **Consider your own constraints carefully** before you agree to undertake developing new information. It is more involved than it seems to be at first and requires substantial time and effort.
- **Find out who in your organisation is responsible for patient information.** Places to try include patient information departments, Patient Advice and Liaison departments (PALS – England only), clinical risk managers, hospital libraries, voluntary services, patient organisations and Community Health Councils.
- **Consider how it will be best to disseminate your information materials:**
 - in admission packs
 - in ward introduction packs
 - by bedside TVs
 - distribution directly via health care professionals directly involved in care (dentists, doctors, nurses, therapists)
 - at health care venues (GP surgeries, PALS, clinic waiting rooms, patient libraries, hospital health information points)
 - through consumer health information services (e.g. NHS Direct, Cancer BACUP)
 - through self help groups and voluntary organisations
 - at pharmacies, health food stores, supermarkets, high street health information points
 - at public libraries, community centres
 - over the internet.
- **Get copies of information materials already in use.** The materials produced during this project – ‘*Anaesthesia explained*’ and ‘*You and your anaesthetic*’ were designed for adoption across the NHS and are available at no charge and without copyright, for use in whole or in part.
- **Look at information materials that have won prizes.** See the BMA patient information competition page: www.bma.org.uk/ap.nsf/Content/LIBBMAPatientInformationAward.¹⁴
- **Contact the Patient Information Forum.** (See Useful organisations, Section 5) and see if there is a member in your area.
- **Look locally and nationally.** Check out leaflet racks and notice boards. What stands out and what attracts your attention? Some of the best materials in the country relating to anaesthesia are presented in Section 2 of this book, and reviewed. Look also for some of the recent information on sensitive issues such as blood transfusion, consent, organ donation and guidance for women on the pill.
- **Obtain relevant guidelines for material development.** The selection we have referenced is a good start and further publications may be available giving guidance on patient information in relation to specialist issues.
- **Consider commercial alternatives.** There are a number of professional producers of patient information (see Useful organisations Section 5).

- **Set your budget realistically.** Include enough to cover meetings, travel, room hire for whatever method of ‘involvement’ you use. For a large or national project, it may be helpful to your set your budget in stages (development, design and production, and review and updating).
- **Schedule meetings early on and close together.** Don’t skimp on them since ‘face to face’ matters for the building of your team as well as effective discussion of issues.

2 Involving people in partnership

Key questions about the team:

- Whose perspectives and skills will help you develop high quality information?
- How will you involve patients, and their representatives, in the team?
- Is there anyone whose omission might affect the credibility and future use of the information?
- Are there any professional or patient organisations you should include from the outset?

2.1 Set up your team

A small team (six to eight) with access to other expertise is ideal. It is important to select the right individuals, which involves finding out about the experience and skills that people have to offer, as well as understanding their motivation and their vision for the finished product.

Just as there are different types of anaesthetists, there are different people who might be called patients, patient representatives, patient group representatives, users, carers or the umbrella term favoured by some, ‘consumers’.

- **Each patient** can speak only for himself or herself, not for other patients. They can offer their knowledge, and important insights, from their recent experience of anaesthesia as it affected them. They are in the best position to judge what information they found valuable in any materials they used.
- **Patient representatives** have wider, and not solely personal, knowledge. They should have a track record of memberships of at least one, and preferably several patient or community groups, often including a Community Health Council. They draw on skills, knowledge and experience from many sources.
- **Patient group representatives** are people appointed or recommended by a patient group to speak for them (e.g. MIND, National Childbirth Trust or Alzheimer’s Disease Society).

Your team should usually include all three types of people. Several anaesthetists, too, are needed to get a range of their experiences and views.

The central team should be made up of two groups, of at least as many patients and patient representatives as anaesthetists. Your team, taken from the following, is likely to be a strong starting point:

Table 1 An overview of key issues from a range of publications

	Kings Fund ⁶	University of Aberdeen ⁷	NHS Toolkit ⁸	Plain English ⁹	DISCERN ¹⁰	CHIQ ¹¹	NHMRC ¹²	BMA Patient Information Award ¹⁴
Development								
How is the information produced?								
Involve patients	■	■	■			■	■	■
Define target audience	■	■	■			■	■	■
Involve experts	■	■	■			■	■	■
Plan budget	■	■	■				■	
Identify evidence base	■	■				■	■	
Plan and establish need	■	■	■				■	
Identify final product/goals		■					■	■
Use unbiased sources							■	■
Test drafts/feedback/evaluation	■	■	■				■	
Content								
Aims clearly stated	■	■			■	■	■	■
Useful/what people want	■	■	■		■	■	■	■
Reliable/current/credible/consistent	■		■		■	■	■	■
Accurate/unbiased/honest	■	■	■		■		■	■
Options and uncertainties stated		■			■		■	■
Level of detail					■		■	
Describe benefits/risks	■	■	■		■		■	■
Describe cause/consequences	■	■			■		■	■
Glossary						■	■	■
Further resources/clear signposting	■	■			■		■	■
Effective communication								
Tone and style	■	■		■			■	■
Achievement of aims/fit for purpose					■		■	■
Respectful	■	■	■		■		■	
Enables shared decision making			■		■			■
Accessibility, availability and timing	■	■	■				■	■
Effective for different audiences	■	■	■				■	
Everyday language (or reference to Plain English* (active voice, first person, short sentences etc.)	■	■	■	■		■	■	■
Presentation								
Impact/appeal								■
Structure/layout			■	■		■	■	■
Clarity/legibility/typeface			■	■		■	■	■
Images/graphics/white space			■			■	■	■
Alternative formats (i.e audio, visual)	■					■	■	■
Quality of presentation (i.e. paper)			■				■	■
Use of colour			■				■	■
Line/sentence length and spacing				■			■	
Minimum font size		12	12	12	12	10	12	
Administration								
Distribution and dissemination	■	■	■				■	
Clear source, author and or sponsor			■			■	■	■
Date, reviews and updates	■		■			■	■	■
Feedback mechanisms							■	■
Monitoring			■					

- anaesthetists and other doctors with relevant clinical knowledge and experience
- individual patients with recent experience of relevant treatment and care
- patient representatives (from for example, hospital patient's forum, Community Health Council's, patient liaison groups, patient councils)
- people nominated by relevant patient organisations or groups.

Whilst it can be difficult to find doctors and patients who have not met in clinical relationships, ideally there should be no current or recent doctor patient clinical relationships between the members of your team.¹⁵

Additional expertise can be sought from:

- other members of the health care team (theatre and recovery staff)
- staff with responsibility for patient information and involvement, quality or audit departments
- non-clinical front-line staff who meet patients during their care (for example, reception staff and hospital porters).

2.2 Identify any skill gaps for which additional support will be needed

Examples of possible areas where the team will benefit from external assistance are:

- research, including formal methodologies, critical appraisal and information searching
- communication, including information handling and basic media production
- project management, which is essential for a larger project, such as the development of a new leaflet series.

2.3 Expenses and subsistence

Skilled patient representatives and people from patient organisations are in great demand. Some form of payment is becoming more common but any arrangements need to respect those in receipt of benefits. It is important to reimburse patients and patient representatives for time, expenses, and reasonable costs of getting hold of the journals, research reports, or other information that they need. Make this as easy a process as possible and be clear about this from the start, so that you ensure that people feel able to claim expenses.

Wherever possible, minimise participants' personal expenses, for example by phoning people back if they call you and enclosing stamped addressed envelopes with any mailings. For a larger or long-term project consider an honorarium or payment in 'kind', e.g. a journal subscription or book token.

2.4 Involving people and ensuring partnership

Health care professionals, health service managers and academic researchers are increasingly urged to 'involve consumers' in research and development activities. This may appear to be motivated purely by political correctness. However, there are good reasons underpinning these requirements.¹⁶

Those working together on producing patient information should treat each other with respect, give each other an equal voice and build working relationships, which are different from doctor patient clinical relationships.

2.5 Ways of working

A range of different ways of working has been encountered. Some of these are described below. Occasionally it may be necessary to use qualitative and quantitative research methods^{17,18} such as focus groups, surveys, in-depth interviews and panels. Section 5 contains further references.

Getting people's views

- 1 A team holds a series of discussions with people who have recently received a particular health care intervention (or have had a particular complication) to find out what kinds of things they would have liked more information about. Some of these people are then invited to join the team to develop and write the information package.

This approach was used to create the '*Headache after an epidural or spinal anaesthetic*' leaflet in the present series.

- 2 A university research unit collaborates with a patient organisation, individual patients and patient representatives to develop an information package. The research unit brings to the partnership the ability to access research evidence, critical appraisal skills and research skills.

This approach was used during the Promoting Patient Choice Programme. One product of this is the '*What should I do?*' publication on ulcerative colitis in Manchester.¹⁹

- 3 A formal questionnaire is developed, then patients act as 'agents' to question other patients about their experiences. Because they can speak only for themselves, working with individual patients requires collecting data from large numbers; and care is needed to ensure a valid sample.

This approach was used in the development of the '*Anaesthetic choices for hip and knee replacement*' in the present series.

Developing and writing

- 4 After agreeing a contents framework, a team of experienced patient representatives writes a patient information leaflet. Healthcare professionals are present to support, answer questions, ensure technical accuracy and identify gaps.

This approach was used to write '*Anaesthesia explained*' in the present series.

- 5 A group is formed of equal numbers of doctors and patient representatives who have worked together before, so know each other well and good working relationships are easily sustained in the new project. Changes to the writing take place at meetings only and each sentence is keenly scrutinised.

This approach was used by the Patient Liaison Group of the Royal College of General Practitioners in 1997 for the '*How to work with your doctor*' leaflets. Consensus was usual and when conflicts occurred the issues were identified, discussed and resolved. The project took 16 months to complete.²⁰

- 6 An information officer for an organisation for people with a particular health problem works in partnership with a hospital team to ensure that the information materials produced address the information needs and concerns of those people in an appropriate manner.

This was the approach used, in partnership with the Royal National Institute for the Blind, when drafting ‘*Having an eye operation under local anaesthetic*’ in the present series.

Piloting

- 7 A patient organisation is identified which has access to patients who have had relevant experience and is asked to assist in organising focus group discussions. Members are asked (i) what they think of existing health information materials, (ii) how they think early drafts of new information materials could be improved.

This was the approach used, with the assistance of a local group of the Arthritis Research Campaign, when piloting ‘*Anaesthesia explained*’ and ‘*You and your anaesthetic*’ in the present series.

Impact evaluation

- 8 A university research unit conducts a randomised control trial to compare those who receive a new source of patient information against those who don’t.

This approach was used in Manchester during research with people with ulcerative colitis.¹⁹

Practical tips

- **Recruit your team carefully.** The quality of the end product will be dependent on the people selected. Before finalising the selection, ask for a short summary of the background and experience of all potential team members, and a list of any publications in which they have been involved.
- **Prepare a clear description of the remit and the constraints** within which you are working. It is important to be able to give this to the people you invite to help you develop and produce information materials, at the outset.
- **Prepare a short reading list** to include (i) texts offering broad guidance,^{1,4,6-14} (ii) local guidelines including house rules and conventions; (iii) samples of existing patient information. This will ensure that the whole team starts from the same baseline.
- **Choose a suitable environment.** Plan carefully how you can make any meetings as relaxed as possible. Consider how many people to include, location (neutral ground is often best), briefing materials, the role or need for a facilitator. Some people will have special needs, for example mobility, food and drink. Clear sign posting and finding a meeting room that suits everyone is important.
- **Try to understand each other’s perspectives early on.** Our team found it invaluable to meet and discuss a range of booklets after each evaluating them individually first. This also contributed to teambuilding and shared commitment. Using a checklist helped give this process some structure and highlighted different perspectives (DISCERN,¹⁰ hospital generated or home grown. You can find the project evaluation questionnaires on the website: www.youranaesthetic.info.

- **Work with local experts.** In many hospitals there will be people who have particular expertise: speech and language therapists, those with skills in communication, public relations staff, medical photographers and illustrators. We found professional editorial assistance invaluable.

3 Developing the content – process, consultation, level of detail

‘I used to think ignorance was bliss. Now my views have changed because detailed information presented well is no longer frightening to me and I feel confident enough to ask questions.’

Patient involved in the Patient Information Project

Questions about content

- How and for what purpose will your reader use it?
- How and when will people get copies?
- What other information do people already get and when do they get it?
- Should anaesthetic information be ‘stand alone’ or integrated into other hospital publications?
- Should you be producing information materials with different levels of detail which cross-reference each other?

3.1 Find out both what patients want to know and what physicians want to get over

Learn as much as possible from and about your target audience. Patients often want to know more detail rather than less. Once people become aware of what could be included they can find it difficult to say what should be left out. Use patients’ questions as a starting point for team discussions.

Literacy is a real issue. In a recent paper from Glasgow one in six people with rheumatoid arthritis attending one centre were found to be non-literate.²¹ This obviously has implications for written information; however a clear script will still be needed to provide the basis for information provided in other formats.

It might be necessary to produce more than one set of materials with different levels of detail in them. The cost of this need not be prohibitive if different options are printed off in-house as required, or perhaps are accessible as choices on the web for readers with access to the internet.

3.2 Produce the first draft

Writing clearly and simply is a skill that only some people have.

Agree:

- who is going to write the first draft. Consider their experience of this sort of writing; would some sort of Plain English or other sort of training be helpful?
- the key messages and their order (‘tell the story as it is’)
- a rough guide to the final word length and print style you are aiming for

- how you are going to handle feedback – on paper, electronically, are all comments going to be transcribed into a table for all members of the group to consider? This is very helpful in making sure that each member of the group keeps a voice and what everyone says is known to all the group
- the number of drafts (aim at five or six maximum)
- the printed format of the first draft
- clear dates for return of comments.

3.3 Consulting and improving on the draft

‘Test your information on the right people. Ignore the views of your colleagues – their comments will almost certainly be criticisms of the content rather than judgements over whether you are getting the right messages across.’

Tim Albert*

Ensure you:

- ask anaesthetists who haven’t been involved in its development to read it, comment and rank it using a quality checklist
- seek external expert opinion – outside your hospital
- ask your intended audience of patients locally
- leave changes until your group has seen all the comments.

3.4 Identify areas of consensus and areas of conflict.

Few guides say anything about how to resolve conflicts of perception, values and interests between doctors and patients, or patient representatives. This sort of work is difficult, so expect some clashes and differences. There are bound to be some areas of disagreement. These need to be talked through and this can take time.

It is often possible to solve issues to everyone’s satisfaction by rewording a paragraph, sentence or phrase. A compromise, leaving out some topics in return for including others, will satisfy no one and should be the last option.

‘If you are not having some areas of disagreement, it is possible that your patient participants either lack experience or are having difficulty voicing their views.’

Member, Editorial Board

3.5 Final editing

Try and ensure that changes to the draft take place at meetings only, and with the team’s agreement.

Then:

- circulate a final paper text copy for people to ‘sign off’
- consider using the Plain English or (equivalent) editing service.

All information should:

- Clearly state its aims and target audience.
- Consider choices and risks in an unbiased way.
- Have contact details and referral on to other sources of information.
- Have a clear date of publication, (author) source, and date.

Practical tips

- **Do your homework.** Our patient representatives and anaesthetists read over 30 booklets on anaesthesia and some detailed website print outs. This was drawn up into a contents framework which told the story of ‘the patient’s journey’, their experience of anaesthesia from start to finish.
- **Get the timing right.** It is better to find out from people ‘what information they want’, away from the immediacy of their hospital treatment. This is more likely to generate honest and useful contributions. An anaesthetist’s involvement in people’s care is often short term. It is tempting for them to ask their patients what they want to know at the wrong time – for example when they have just come into hospital, or are just about to go home from day surgery.
- **Ask colleagues how they describe things to their patients.** Many anaesthetists have found ingenious solutions. A word or phrase that one person has developed to describe their practice may be just the phrase you are looking for. *‘The more I incorporated ideas that at first seemed a bit odd, troublesome or risky, into my own working practice, the more confident I became, based on feedback of patients. I found that pausing and listening more, sharing drug PILs, especially for drugs that have troublesome side effects and making a habit of talking about risk of awareness and serious injury or death’.*

Consultant anaesthetist

- **Use a standard format first.** A lot of word processing time can be wasted changing the format of drafts and incorporating change. To produce an A5 booklet we found using a plain A4 page with large font (say 16pt) was the easiest. It is easy to comment on and, once agreed, reduces simply and quickly to an A5 paper booklet in a modern photocopier with a ‘booklet program’. At this reduced size, the font size also approximates to 12pt, which is recommended to ensure the legibility of the final production. Sometimes paper copy with line numbers is the quickest.
- **Editing.** Small changes can make subtle but crucial differences.

For example:

Original	Your anaesthetist will talk with you about what anaesthetic methods are possible and find out what you would like.
Edit	Your anaesthetist will discuss with you what methods are possible for you.
Agreed version	Your anaesthetist will discuss the anaesthetic methods that are appropriate for you and will find out what you would like.

- **Agree email and other computer conventions:**
 - email can be quick but risks overburdening some people and/or excluding others, which can make keeping track of different versions difficult
 - all changes to the text (edits) that members want should be made clear, with the reasons for them

- agree and exchange computer tips before starting, particularly the insertion of notes and tracking changes
- use telephone conferences with care and save them for small numbers of people (under five).

4 Communicating clearly – writing, design and printing

Questions to consider

- Do you know your hospital’s house print style?
- Are there any templates?
- Does your hospital use the draft NHS templates for patient information?
- Who is going to look at your final print, proof-reading it for the ‘first time’?

The content, tone, style of writing and design all matter. All four elements contribute to how effective the communication is.

4.1 Tone and style of writing

- Use simple and clear English. Plain English Guidelines recommend the active voice and short sentences.⁹
- Be structured and concise, use clear headings and bullets to break up the text and try and tell the story in the order that it happens.
- Beware of confusing messages. Are you saying one thing in one place and contradicting it somewhere else? It is helpful to build up a glossary of standard terms and descriptions of common procedures, so that they are always referred to in a consistent way.
- Try and give specific instructions rather than general ones. Avoid negative statements and talking down to patients.
- Communicating uncertainty is a complex subject and covered in Communicating Risk Section 3.
- Reading scores may be helpful. Three common ones are the Fog readability index, the Flesch Scale and the SMOG scale. These are fully described in other publications.²² The simplest one to use is the Flesch score, which is available on many word processing packages including Word 97 (look up readability statistics in the Help index).

4.2 Text layout and overall design

Keep the design in the background. Good design is simple and should be an integral part of the publication.

- **Fonts** – The Department of Health toolkit⁸ specifies particular fonts (Arial or Frutiger). These can be downloaded from the website. No more than two or three fonts should be used per document. Your audience should determine the font size. Most guidelines recommend 12 point as a minimum. Older people and people with poor vision will need a larger font size.
- **Capitalisation** – Keep capitalisation to a minimum. Lower case letters are easier to read in blocks of text.

- **White space** – White space matters, don’t be tempted to fill the whole page. The distance from line to line of text (known as ‘leading’ or ‘line feed’) should be greater than your point size. Larger margins and left justification increase the text readability.
- **Highlight important sections** in some way – Use colour, boxes and icons to draw the eye in.
- **Background** – Background colour is often pleasing, however, the contrast between the colour and the text needs to be sufficient. Keep backgrounds plain and try to avoid printing text over pictures or photos.
- **Graphics** – Simple pictures enhance publications but getting pictures that appeal to everyone is not that easy. The Department of Health toolkit⁸ recommends avoiding clipart. Pictures should relate to the text around them.
- **Alternative options** – Remember to consider the other media options available, to ensure wide readership. These may include CDs, audio tapes, or video.

4.3 Getting to ‘print ready’ stage

If you are going to print your materials using an external designer and/or printer, the likelihood is that they will be using publishing software which will not be on your work pc. If you use email to receive draft designs, this means that you will need to use pdf files (portable document format), which are readable with Adobe Acrobat Reader, freely available software.

As with your earlier drafting of the text, it is important for someone in your team to have clear ‘sign off’ authority, so that time is not wasted with the designer/printer pursuing different versions for different members of the team.

Review proofs carefully, checking all details.

- **Cover and paper** – Consider a good quality paper/card for your cover, particularly if your publication will be handled frequently. Matt paper is easier to read from. The NHS recommends 120 gsm (grammes per square metre) as a minimum thickness.
- **Circulation and publicity** – Plan this early on. Think about alternative outlets for your information.

Practical tips

- **Encourage creativity.** Don’t be restricted either in content or in design by what has already been published.
- **Invest in good design.** Seeking professional editorial assistance outside the original team can provide invaluable expertise Getting someone fresh to review your work near the end is essential and helps pick up errors and inconsistencies.
- **Decide on the style of graphics early on.** Acquire medical illustrations and simple anatomical drawings at the beginning of the project. These should make things easier to understand and will need testing out with patients. Leave the commissioning of other artwork until quite late, but find your artist and agree the styles as early as possible. The final artwork will depend on what is written and how the text sits when it has been designed and laid out.
- **Look out for relevant research and guidance** on the production of clear information materials.

5 Evaluation

'I now realise how ignorant I was before doing this project, about where all the expertise on this was, about what had been written, about what systems existed to develop and authorise patient information, even in my own hospital. I have learnt a lot how colleagues would react when faced with information and attitudes based on different value systems and perspectives.'

Consultant anaesthetist

Developing patient information is part of a continuing process. Once started there remains a need to:

- collect feedback on your information materials
- audit the use of them
- update if there are significant changes in practice or evidence
- review at regular intervals – perhaps two yearly
- continue to develop and publish information for specific situations.

Feedback can be requested, published openly, scrutinised and any changes to future printed editions agreed by anaesthetists, patient representatives and patients.

Acknowledgements

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- 1 The University of Aberdeen Health Services Research Unit for permission to use information from their on-line guide.⁷
- 2 The Communications Unit at the Department of Health who have recently published a *'Toolkit for producing patient information'*⁸ which includes guidance and design templates for the production of written information for patients in for the NHS. We have been kept constantly updated on these during their development.

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The development of specialist booklets

Dr Anna-Maria Rollin

Introduction

From the outset of The Patient Information Project, the Editorial Board decided to produce two core booklets, ‘*Anaesthesia explained*’ for display in outpatient clinics, wards, waiting rooms and doctors’ surgeries, and ‘*You and your Anaesthetic*’ for sending out to individual patients. The first would be a fairly comprehensive source of information about anaesthesia, while the second was designed for people who are booked for surgery, to inform and enhance the consultation between the individual patient and his or her anaesthetist.

In addition, we decided to produce a series of booklets on selected specialist topics. Our objective was to try to formulate a template or templates on which such booklets could be based, and to design and test a process which could be used by other people to produce their own specialist booklets as the need arose. This chapter describes the process and the principles and draws together some of the learning from those involved.

The process

Choosing the topics

The choice of subjects was difficult. It goes without saying that the number of possibilities was huge. We were keen to provide a spread of topics, so that we could try out different ways of producing booklets and involve a large number of people in their production.

The original project brief excluded the clinical areas of intensive care and chronic pain management. After extensive discussion, the Editorial Board decided to focus on the following aspects of patient information:

- Addressing a target audience (e.g. parents).
- Describing a particular procedure (e.g. spinal or epidural anaesthesia).
- Discussing a clinical specialist area (e.g. eye or aortic surgery).
- Describing a fairly common complication (e.g. post-dural puncture headache).
- Addressing an area of perceived, and partly media-driven, anxiety (e.g. dental anaesthesia).
- Describing an area where patients may exercise real choice (e.g. regional or general anaesthesia for hip or knee replacement).

Inevitably, as in real clinical practice, there was overlap between the areas chosen. The topics finally chosen were:

Your child’s general anaesthetic.
Your spinal anaesthetic.
Epidurals for pain relief after surgery.
Headache after an epidural or spinal anaesthetic.
Your child’s general anaesthetic for dental treatment.
Local anaesthesia for your eye operation.
Your tonsillectomy as day surgery.
Your anaesthetic for aortic surgery.
Anaesthetic choices for hip and knee replacement.

Clearly, this list is far from comprehensive and no attempt was made to cater for patients with special needs, be they learning difficulties or special linguistic or cultural requirements. This is work for the future.

In addition, the sharp-eyed will spot that the titles of the nine booklets vary in different places. Titles were suggested by the Editorial Board in the first instance. As the work progressed, it became apparent that some of the titles needed modification to reflect the actual content of the booklets. The project took over two years to complete, and individual booklets have been published and placed on the website (www.youranaesthetic.info) as they were completed. It was never our intention that the end result should be static: rather the reverse. It was always planned that the project should evolve. In keeping with this spirit, where titles needed changing from the originals, we have done so. Since all the text may be used by Trusts and departments of anaesthesia as they wish, with or without modification, it seemed sensible to grant the same freedom to our authors.

The specialist leaders

A ‘specialist leader’ was invited to head the group producing each of the specialist booklets. Each of these leaders is a consultant anaesthetist who has acknowledged expertise in the field. Each was identified either by, or with the full endorsement of, the relevant specialist society.

Each specialist leader was contacted personally and asked to participate. Responses varied. At one end of the spectrum, there was the eager enthusiasm of those who had already produced or were planning to produce patient information, were converted to the principles of using good patient information as a tool for communication and to drive forward the NHS consent initiative, and were pleased that the Royal College of Anaesthetists and the Association of Anaesthetists were taking an active role in the process. At the other end of the spectrum were those who felt slightly ‘press-ganged’ by the project, and expressed some reluctance to be involved in what they saw as a politically-motivated exercise. Nobody refused to participate.

During the process of writing, there was some movement from one end of the spectrum to the other, mostly in a positive direction.

Initially, the specialist leaders were asked to begin thinking about their topic, to change or refine the title they were given and to begin to research existing material. They were also asked to consider how they might assemble a team to write the leaflet.

To help this process the group leaders were invited to a consultation day at the College. They were asked at this early stage to identify a 'lead patient' or patient representative on their team, who was also invited to the meeting.

The active involvement of patients and patient representatives has been a feature of this project throughout. Much of the material has been written by them, with anaesthetists acting as technical advisers.

The specialist leader pack

On the consultation day, time was set aside for the specialist leaders to meet as a group to discuss the process. Each was given a ring binder containing the following information:

1 Advice on getting started

This section included an outline of the development process, how to select and recruit a group of five to eight people to write the leaflet, and an outline of what the leaflet should include.

2 Letters and templates

Template letters to chief executives, patients and patient representatives, explaining the project and requesting cooperation or participation.

3 How to do it

The University of Aberdeen guide to producing patient information.¹

4 Literature review

A literature review of the evidence for patient participation in the production of patient information, now developed more fully into the 'Resource Guide' (see Section 5).

5 Evaluation guide

This section contained the questionnaire developed by the evaluation team, a report from the patient representatives group on their evaluation and a list of 'jewels and howlers' – terms, phrases and descriptions identified by patient representatives and anaesthetists as being especially helpful or unhelpful in the information given to patients.

6 Draft chapters

Draft chapters on 'Risk communication and anaesthesia' by Andrew Smith and Anthony Adams and 'The patient perspective on information' by Charlotte Williamson were included (see Section 3).

7 Published quality checklists

Guidelines for assessing quality of health information, including those from the Centre for Health Information Quality (CHIQ), the DISCERN guide, and some of the key principles from The POPPi Guide published by the King's Fund were included in this section.^{2,3,4}

8 Relevant patient information

Each specialist leader was given selected patient information booklets from the College archive relevant to the topic under development.

9 Best booklets

30 booklets which had scored highly on evaluation were included as examples of 'good practice'.

Following the consultation day, the specialist leaders and their identified patient representatives were asked to work to a very tight schedule. The project co-ordinator, Sue Parroy, was able to offer a limited amount of administrative support with photocopying, postage and design advice. She also offered an unlimited amount of moral support and encouragement.

Production of the booklets

Once the specialist leaders had identified their teams, writing could begin. The first draft was written by an anaesthetist but a large number were guided in this by priorities identified by the patients and patient representatives in the group.

This first draft (V1) was modified and agreed by the specialist team and the second draft (V2) was sent to the project editorial and advisory boards. They in turn returned their comments to the specialist leader and the team produced a third draft (V3).

This draft went to the member of the Editorial Board nominated as the specialist leaflet editor (Anna-Maria Rollin), who edited it for consistency with '*Anaesthesia explained*' and '*You and your anaesthetic*'. She sent this fourth draft (V4) to two further readers, one an anaesthetist and one a patient representative, as well as to the specialist leader for a final check. Any changes were incorporated into a final draft (V5), which was then deemed fit for professional design and printing.

As the draft booklets became available the consultation day participants and anyone else who had expressed an interest were notified and copies were sent on request. This provoked some interest from a range of people, including a number of non-anaesthetists. Comments received through this route were taken up and acted upon where appropriate.

Editorial principles

The booklets were edited for factual accuracy and for consistency with the terms and descriptions used in '*Anaesthesia explained*' and '*You and your anaesthetic*'. This was to try to minimise the potential for confusion and conflicting information. Other than that, they were left essentially as the authors had written them. This resulted in a variety of styles, different modes of presentation and a variable depth of academic content. That was exactly what the project team intended. There is no 'right' or 'wrong' way of presenting patient information, just as there is no 'average' patient. It is hoped that readers of this book will find an approach which suits them and their patient population.

The group producing the leaflet on 'Your tonsillectomy as day surgery' found great difficulty in producing a single leaflet for adult and child patients. There are therefore two versions of the leaflet available, one for adult patients (reproduced here) and one for the parents of small children which will be available on the website. In future, it will be useful to produce booklets aimed at children themselves.

Format

It was decided that the booklets should be presented in a uniform format, to reinforce that used in 'Anaesthesia explained' and 'You and your anaesthetic'. This format may be modified by users at will.

The only exception to this decision was the leaflet on 'Headache following epidural and spinal anaesthetics'. The group which produced this felt very strongly that it should be short enough to be contained on two sides of a single sheet of A4 paper, which could be folded into three, making a compact leaflet. We have produced it in this form, to give readers the possibility of another variation, and to compare a very short leaflet with some of the longer ones.

The text of all the booklets is reproduced in this book. In addition, there are designed and printed versions of 'Your child's general anaesthetic', and 'Headache after an epidural or spinal anaesthetic'. The website and CD contain the text in a number of different file formats to allow ease of access and use.

How was it for you?

Specialist leaders were sent a questionnaire to fill in at the end of the process, so that they could share the lessons they had learned. Eight out of the nine leaders provided feedback, although not all of them used the questionnaire or answered all the questions. Below is a summary of the responses.

The specialist leader pack

All found the pack helpful, although (predictably) some said they used it more extensively than others.

The practical advice on getting started was universally welcomed and used. So were the 'jewels and howlers' identified by the Patient Representatives Group in their evaluation of the material collected by the College. Five specialist leaders reported that the material from the archive relating to their subject area was useful. One reported that it was not.

Responses to the 'academic' content of the pack varied. The 'academic' or theoretical content included a 'How to do it' guide from the University of Aberdeen, a literature review, draft chapters on risk and the patient perspective and published, authoritative checklists for assessing the quality of health information. Views were approximately evenly split. Some found many of them helpful; others clearly found them annoying and inhibiting.

The team

Patients and patient representatives

Most groups found that the patients and patient representatives set the 'agenda' and the tone of the leaflet. They were instrumental in weeding out jargon and simplifying the

approach. Interestingly, 'actual' patients were more inclined to play down the risks and soften the tone than were either patient representatives or anaesthetists.

All the specialist leaders reported that the booklets would have been quite different had patients and their representatives not been so closely involved, and all felt that their presence had been an enormous benefit.

Other healthcare professionals

Surgeons were useful in providing technical details for those booklets which targeted specific procedures. Nurses, as members of the healthcare team who often end up explaining things to anxious patients, provided a useful insight into the things which actually worry patients.

Others

Most teams which incorporated members of Community Health Councils, Patient Advocacy and Liaison Services (PALS) and hospital communications officers found that they brought special skills in formulating and testing patient information materials which much enhanced the finished product. However, there was a need in some groups to edit out contributions clearly designed to advance a personal or 'political' agenda.

Almost all the groups used random patients, patients' parents, colleagues and spouses as ad hoc sounding boards and proof readers.

What worked well

There was an unanimous view that a locally recruited team, working with guidance and backup provided by the Royal College of Anaesthetists, was an effective way of producing high quality patient information, tailored to local needs.

What worked less well

Each of the specialist leaders felt that in the end their group had worked through the difficulties, and had now evolved a process which was repeatable. However, many had travelled down time-consuming byways and felt they were reinventing the wheel. There was an expressed need for a straightforward framework on which to base the information-writing process. In working through the process, of course, each group has contributed to the production of this framework, which is in many ways the purpose of the whole project.

Extra support required

Most group leaders felt that they could have done with more technical and clerical help. Requests included secretarial help to get round the problem of two-finger typing, a research assistant to trawl through the existing literature and the availability of an illustrator or graphic designer from the start. (We were fortunate in enlisting the help of Stephen Young later in the project).

One group leader felt that participants should be paid for their time. As he put it: 'Goodwill provides little in the way of carrots and nothing in the way of sticks.'

‘Top Tips’

The specialist leaders were asked what advice they would pass on to someone about to start developing patient information. There was a remarkable degree of consensus. The following are the ten ‘top tips’:

- Choose a subject which interests you, research it thoroughly and set the boundaries of your project at the outset.
- Recruit a small, carefully selected group with a wide range of skills.
- Beware (but incorporate) enthusiasts, experts and those with axes to grind.
- Start writing. Write well or badly, but write now.
- Use simple English.
- Tailor the level of detail to your target audience.
- Present all information from the patient’s viewpoint.
- Agree a style and format. FAQs and bullet points are popular.
- Be humble – take lay views seriously and incorporate them whenever possible. That said, it is important to retain editorial control.
- Road test the results on real patients whenever possible.

Future role for the College and the Association

All the specialist leaders felt that there was an important future national role for the RCA and the AAGBI in the updating and development of copyright free patient information. This was to ensure consistency and prevent people from having constantly to reinvent the wheel.

There is a requirement on Trusts to provide information on anaesthesia to inform the consent process.

The lessons we learned

Involvement of patients and patient representatives

From the outset, nobody on the project team or in the specialist groups needed convincing that it was not only desirable but essential that we work closely with patients, patient representatives and patient groups. However, many people had little experience of this in practice, and it was easier said than done.

Patients and patient representatives were not always easy to recruit. They are almost invariably volunteers, and the project was heavy on time. The project budget was able to provide some modest funding for expenses, but not for patients’ incidental costs like telephones, stationery and secretarial work.

There is a world of difference between ‘patients’ and ‘patient representatives’, although the two categories may overlap. We were all conscious that it was undesirable for any patient working in a specialist group to be in, or have recently been in, a ‘doctor patient’ relationship with any anaesthetist or other doctor in the same group. Even so, quite often patients reported that they felt intimidated and were reluctant to put forward their ‘amateur’ views in a group of professionals.

This problem was largely overcome by good leadership and by having more than one patient in the group. The ratios varied, but half and half seemed to be a ‘liberating’ proportion.

With patient representatives, the problem almost appeared to be the reverse. Patient reps are often articulate, knowledgeable and determined people. They have honed their arguments over time. Regrettably, some of the doctors felt that they were being treated like the enemy, and that their expertise counted for nothing.

All the groups which produced booklets worked successfully through the acknowledged problems. Some, where patient representation had been modest, felt that more would have been beneficial. Some of the booklets were produced largely by the patients and representatives, with the healthcare professionals acting as technical checkers.

Wider consultation

Multidisciplinary working is now the norm within the NHS, and nobody had any difficulty with involving as many people from as many backgrounds as possible. Surgeons and nurses were particularly valuable when writing the technical portions of the booklets, since they see the same problems as the anaesthetist, but view them from a different perspective.

All hospitals now have PALS officers, some hospitals have communications officers, most have risk managers. Many of these people have specific training and experience in writing for patients, and proved very valuable in the actual production of the booklets.

Representatives of the Community Health Council bring with them knowledge of the local patient population, especially those portions of it which are unlikely to find their way on to a group writing information booklets.

No group managed to recruit a local general practitioner, although a few of the specialist leaders expressed regret at that.

Several of the specialist leaders reported that excess enthusiasm from a member of the group representing a narrow special interest needed curbing. They all succeeded in doing so, with varying degrees of tact.

All the booklets were shown, informally, to all sorts of people – patients, healthcare professionals, secretaries, porters; the man on the Clapham (or at least the local) omnibus. The feedback was valuable and was used in refining the leaflet contents.

Specialist organisations

All the anaesthetic specialist organisations were contacted early in the project, with details of what was proposed. They were all invited to be involved, and many sent representatives to the consultation day. Similar information was sent to the other Royal Colleges and as many of the relevant professional organisations as we could identify,

The specialist leaders were all nominated by, or received the endorsement of, the appropriate specialist organisation.

Where possible, the specialist booklets were sent for comment and endorsement to appropriate non-anaesthetic bodies. For example, the Royal National Institute for the Blind (RNIB) was enormously helpful in the production of ‘*Local anaesthesia for your eye operation*’ and provided expertise which would have been difficult to find elsewhere.

Where such collaborations and endorsement have taken place, the logo of the organisation is displayed on the leaflet along with the RCA and AAGBI logos.

Inevitably, the list of organisations we consulted was incomplete, and several of the excluded organisations contacted the project team. Throughout the project we have tried to include all who wished to participate, and an apology for the oversight usually elicited an offer of help and valuable comment.

At least one surgical organisation, however, felt that we had overreached ourselves and wandered into territory not properly our own. An invitation to collaborate was declined.

Drafting the booklets

It was the experience of the specialist groups that producing the booklets took longer and was more complicated than they had anticipated.

All aimed for simplicity; all found it hard to achieve.

The greatest difficulty lay in reconciling the differences between individual members of the groups as to the level of detail required. This applied especially to risks and potentially adverse outcomes.

Editing the booklets

The first decision the Editorial Board had to make was whether to allow and encourage the individual voice of the author or to edit the booklets according to a rigid formula, to achieve consistency.

We decided on the former, for the following reasons:

- The subjects chosen were deliberately disparate.
- The target audiences were, therefore, different (for example, parents, elderly people having cataract surgery, new mothers who had had epidurals).
- We aimed for a wide geographical spread, to allow for regional differences.
- Specialist leaders chose their own teams, within a loose framework suggested by the project team.
- We wanted to try out different forms of patient information, and different methods of producing it.
- Producers of patient information would be encouraged to use the material as it appeared or to modify it as they saw fit, so there was no need for a rigid format.
- We really didn't know which of the many possible formats was best, and part of the purpose of the exercise was to work this out.

Part-way through the project we acquired the services of a professional editor and designer, and he edited a number of the booklets into a standard format. There is no doubt that these achieved a degree of elegance and a level of consistency which was lacking in the booklets not so treated. However, we stuck to our original decision to let the specialist groups speak for themselves.

As editor, I discovered that there was always more comment on the drafts than I had anticipated, and there were far more sensibilities to be offended than I would have thought possible. Great tact was required when amending other people's carefully honed prose, and I left it alone wherever possible.

Email proved a double-edged sword. It is, of course, much cheaper and quicker than sending hard copy through the post, and that is both its strength and its weakness. Some people tended to fire off comments on drafts more or less instantaneously. Others mulled them over for a while. Since all members of the group received everything, soon there were versions flying around all over the place. When it came to the final edit, it was done in ink, on paper.

It was necessary to introduce an arbitrary cut-off point for comments. Because the work was done in groups, and then tested on various organisations and individuals in an unlimited way, comments kept coming in. These were all welcome, and mostly valuable. Nevertheless, there came a point where a line had to be drawn under each leaflet.

Fortunately, the patient information project was never intended to be a static thing. All the material is available on the website, and modifications can be made as frequently as necessary.

We hope that it will remain a 'work-in-progress'.

Controversies

Inevitably, given the number of people from different backgrounds involved in the work, a number of controversies arose. The most important are listed below:

Length of booklets

Everybody agreed, in principle, that short was better than long. However, there were protracted discussions about the level of detail required, and how often one might legitimately use the phrase 'If you want to know more about this, ask your anaesthetist'.

The discussions also hinged around the purpose of the booklets. Were they primarily for information, education or reassurance?

Interestingly, patients often wanted less rather than more information, while patient representatives wanted to include all that was known about a subject. Anaesthetists, on the whole, went for the middle ground, but were keen that patients should be told the things that they needed them to know (fasting, methods of induction, post-operative pain relief).

The working compromise was the production of '*Anaesthesia explained*' as a fairly comprehensive guide which could be made available in outpatient clinics and doctors' surgeries, '*You and your anaesthetic*' as the booklet which could be sent out to all patients booked for surgery, and the specialist booklets to supplement either or both of these.

Nevertheless, it is fair to say that all the booklets grew during the production process, with the exception of '*Headache after an epidural or spinal anaesthetic*', whose authors stuck firmly to their guns.

The 'Sleep' Controversy

Most of the anaesthetists involved in the project admitted cheerfully that they used the word 'sleep' when they referred to a state of anaesthesia. Most of the patients did likewise. A few positively disliked the word 'unconsciousness', finding it scary.

However, all the patient representatives and a few of the anaesthetists found the word 'sleep' unacceptable in this context. They made the point that anaesthesia is not synonymous with sleep, and that it was patronising to suggest that patients should not be told, or might not understand, the difference.

The word 'sleep' is not used in the booklets to signify a state of anaesthesia. It may take a while longer to remove it from colloquial parlance.

Side-Effects and Risks

It is a requirement that the information given to patients to inform the consent process should refer specifically to risks.

There was long debate about what risks and side-effects should be included, and what the terms 'very common', 'common', 'uncommon', 'rare' and 'very rare' meant in numerical terms. (see 'Risk communication and anaesthesia' Section 4).

There were widely divergent views on where useful information to aid the decision making process ended, and scaremongering began.

A common linear analogue scale, illustrating risk, has been included in all the booklets for consistency. Each of the specialist groups devised their own list of side-effects and risks, based on the best evidence available, and these were modified to fit in with the lists in '*Anaesthesia explained*' and '*You and your anaesthetic*'.

Conclusion

The specialist groups who produced the booklets were innovators working in largely uncharted territory. They coped with moving goalposts, harsh deadlines and criticism from strangers with remarkable equanimity. They have produced a body of work which will be useful, and will increase in value as it is honed by use. To quote one of them:

'I will probably gain more from the process of preparing the information than any patient will gain from reading it. It has forced me to put myself into the patient's shoes.'

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