

**Producing
information about health
and health care interventions:
a practical guide**

Máire O'Donnell
and
Vikki Entwistle

Health Services Research Unit
Medical School University of Aberdeen Foresterhill Aberdeen AB25 2ZD
Tel: +44 (0) 1224-681818 Fax: +44 (0) 1224-663087

Contents

| | |
|---|-----|
| Acknowledgements | iii |
| About this guide | iv |
| What is the guide for? | iv |
| Who is the guide for? | iv |
| How is the guide organised? | iv |
| How might you use the guide? | iv |
| How comprehensive is the guide? | v |
| Part I: Why is health information important and what makes for good quality health information? | |
| Why is health information important? | 1 |
| Why do people need information about health and health care interventions? | 1 |
| How can information help? | 1 |
| What makes for good quality health information? | 3 |
| A clear statement of aims | 3 |
| Relevance of information | 3 |
| Accuracy of information | 4 |
| Accessibility, comprehensibility and acceptability of information | 5 |
| Information for patient-focused services | 5 |
| Fitness for purpose | 6 |
| Helping people to identify further sources of information and support | 6 |
| Helping people to judge the quality of health information | 6 |
| What makes for good quality information provision? | 7 |
| Part II: Producing good quality information materials | |
| Before you commit yourself.... | 9 |
| Initial thoughts about information materials | 9 |
| What are you thinking of producing? | 9 |
| Do people want or need information on this topic? | 12 |
| Does a suitable information package already exist? | 12 |
| Do you have the necessary skills and resources? | 13 |
| If you decide to proceed... | 13 |
| An overview of the production process | 14 |
| Informing the content of information materials | 15 |
| Information about your audience | 15 |
| Information about the context(s) in which the information will be used | 16 |
| Finding the different types of information you need | 19 |
| Research evidence about people's experiences and views of health conditions and health care interventions | 19 |
| Research evidence about health conditions and health care interventions | 19 |
| Clinical practice guidelines and standard documents | 20 |
| Information about patterns of practice | 20 |

| | |
|--|-----------|
| Health coverage in the popular media | 20 |
| Voluntary organizations | 21 |
| Members of your intended audience | 21 |
| Health care professionals | 22 |
| Producing a first draft | 24 |
| Ways of making your information materials more useful and acceptable | 24 |
| A clear statement of aims | 24 |
| Information about further sources of support and help | 25 |
| Issues relating to language | 26 |
| Communicating probabilities | 27 |
| Making information accessible to people with special communication needs | 27 |
| Communicating research evidence about the effects of health care interventions | 28 |
| A lack of research evidence or lack of clear answers from research evidence | 28 |
| Uncertainty about who will benefit | 29 |
| The contested importance of usefulness of the research evidence | 29 |
| The disputed applicability of the research evidence | 30 |
| What about interventions that might not be available? | 30 |
| Eliciting and incorporating feedback on drafts | 31 |
| Whose opinions should be sought? | 31 |
| How should opinions be sought? | 32 |
| How should feedback be handled and used? | 34 |
| Post-distribution reviewing and updating of information materials | 35 |
| Useful references and organizations | 36 |

Acknowledgements

The first version of this guide was produced in 1999. We thank staff at the Centre for Health Information Quality who helped identify references for the first version. We also thank the following people for helpful comments on drafts of that version: Sarah Buckland, Mary Flora Conner, Patricia Dawson, Adrian Grant, James Inglis, Ray Jones, Lindsay MacHardy, Clare Pillar, Anne Walker, Ian Watt.

This second edition of the guide was produced in 2003. The update incorporates issues identified during the development of three information leaflets on the removal of wisdom teeth, the option of withdrawal from or continuation with anti-epileptic medication and the treatment of 'intermittent claudication' for use in NHS Scotland. We thank the various health care professionals, members of voluntary organizations, and people with experiences of the relevant health conditions who gave generously of their time and expertise to help develop these leaflets. We also thank the following people for helpful comments on this second edition: Graham Bell, Pauline Cumming, Sushee Dunn, Ken Ferguson, Mairi McMenamin; Rona Smith.

The production of the first version of this guide was funded by a project grant from the Health Planning and Quality Division of the Scottish Executive Health Department in 1998. The Health Services Research Unit is core funded by the Chief Scientist Office of the Scottish Executive Health Department. The views expressed in this guide are not necessarily those of the funders.

About this guide

What is the guide for?

The guide aims to give useful ideas and practical advice about how to assess, develop and revise information materials about health and health care interventions for patients, their families or members of the public.

The guide focuses on the *content* of information materials. It pays particular attention to the quality of information about the effects of health care interventions.

The guide is one of a series of initiatives supported by the Scottish Executive Health Department to help improve the quality of information provision within NHS Scotland.

Who is the guide for?

The guide should be useful to anyone who is involved in assessing, developing or revising information materials about health and health care interventions for patients, their families or members of the public. We have prepared it particularly for people working within or with NHS Scotland.

How is the guide organised?

The guide is divided into two main parts. Part I considers the main features of good quality health information. It starts by explaining why information about health and health care interventions is important. It then discusses key aspects of the quality of information materials. It concludes with brief comments about the policies and systems that health care professionals might use to ensure appropriate use of good quality information materials.

Part II outlines the basic steps involved in producing good quality information materials. It discusses what is required during the planning of health information materials, the production of first drafts, and the refining of drafts to make sure the final materials are as good as possible.

We have provided a list of useful references and organizations, including those mentioned in the text, at the end of the guide.

How might you use the guide?

If you need to assess the quality of existing information materials, we suggest you read Part I. This should give you some useful ideas about the kinds of criteria you might want to consider. You could also check out some of the checklists of information quality that are listed at the end of the guide.

If you are thinking of developing new information materials, we suggest you read the whole guide once before you start. The first few sections of Part II encourage you to check that there is not already a good quality information package that will serve the purpose you envisage. The remaining sections of Part II take you through the main stages of the development of the content of an information package. If you decide to go ahead and produce a package you can return to particular sections of the guide as you proceed.

If you are planning to revise existing information materials, we suggest you read the whole guide once before you start. You can then consider particular issues in more detail by returning to the appropriate sections as you proceed. Although you are not 'starting from scratch' to develop an information package, many of the issues that are covered in the early sections of Part II remain relevant as you obtain feedback on the package you plan to revise.

How comprehensive is the guide?

The guide is not a comprehensive information production manual. As mentioned above, it focuses on the development of the *content* of information materials. The stages of production that the guide refers to are those for the production of text-based information, and we have not provided technical details about how to use different media. We have not devoted much space to issues relating to information presentation because these have been well-covered in other guides and local/corporate protocols.

Part I

**Why is health information
important and
what makes for good quality
health information?**

Why is health information important?

Good quality information is an integral part of good quality health care. The Scottish Executive Health Department regards good quality information as an essential feature of the patient-focused services that NHS Scotland is striving to provide.

Why do people need information about health and health care interventions?

People need information about health and health care interventions for various reasons. For example, they might want information so they can:

- Understand what is wrong with them;
- Understand what particular tests and treatments involve and what their outcomes might be;
- Contribute in a more informed way to discussions or decisions about their care;
- Care appropriately for themselves and their families;
- Know when to seek professional help and be able to make the most of consultations;
- Be reassured and feel able to cope;
- Explain to others (for example, families, friends or employers) what is wrong with them and what treatments they might need;
- Identify further sources of information, self-help groups, or health and social care professionals who can offer appropriate services and support.

How can information help?

Good quality information can:

- Help people to help themselves by:
 - Explaining the health implications of particular behaviours;
 - Improving their ability to identify and cope with practical and emotional problems;
 - Giving them the knowledge and confidence to self-treat when appropriate;
 - Enabling them to seek out effective forms of professional help or lay support.
- Help people to get more out of professional health care by:
 - Familiarising them with the types of issues that they might need to discuss with health care professionals;
 - Helping them to understand what they are told by health care professionals
 - Helping them to formulate and ask relevant questions;
 - Making them aware of the types of treatment and standards of care that should be offered.
- Make people feel better because they:
 - Know that their problems are real and recognised;

- Feel better able to cope with their problems and identify ways of improving their situation;
 - Understand what their treatment involves and why they need it;
 - Feel more confident and in control.
- Enable people to give informed consent to health care procedures.

What makes for good quality health information?

Much has been written about the quality of health information materials and various checklists have been produced to help assess different types of materials. Some of the key features of good quality information are listed in the box and discussed below.

Good quality information materials:

- Clearly state what they are about and whom they are for
- Are relevant to the people for whom they are intended
- Are accurate (and especially are consistent with up-to-date research evidence about the effects of health care interventions)
- Are accessible, comprehensible and acceptable to the people for whom they are intended
- Support patient-focused health care
- Are fit for their purpose (well designed to achieve their particular aims)
- Help people to identify further sources of information and support
- Help people to judge the quality of the information provided

A clear statement of aims

People will be better able to judge whether information materials are likely to meet their needs if they include a clear statement of what they aim to achieve, what they do and do not cover, whom they are intended for, and (if necessary) to whom they do not apply.

Relevance of information

Health information materials should first and foremost be useful to the people for whom they are intended. They should meet their audiences' information needs. In the past, health care professionals and other information producers tended to assume that they knew best what information people needed and wanted. Unfortunately, many of the health information materials they developed failed to address issues that people thought important.

The types of information that should be included in an information package on a particular topic will depend on its aims and intended audiences. Although there is some consensus about the basic types of information that people need in particular situations, opinions will vary about precisely what information should

be included in an information package. People vary in terms of the importance they attach to information on particular topics and the level of detail they prefer.

Accuracy of information

Health information materials should be accurate. Accuracy, however, can be a difficult quality to pin down. Some of the most common failings of health information materials that have led them to be judged 'inaccurate' have related to the provision of information about the effects of health care interventions. Materials have been criticised because:

- they fail to provide sufficient information about the possible outcomes (benefits and potential risks and side effects) of health care interventions.
- the information they do provide about the outcomes of health care interventions is not consistent with the best currently available research evidence;
- they give the misleading impression that there is complete certainty about the effects (particularly the benefits) of health care interventions

Other aspects of accuracy that are particularly important in information materials about health and health care interventions include:

- the extent to which information about health care processes is consistent with what is currently recognised to be 'best practice' (for example as outlined in up-to-date research-based clinical guidelines);
- the extent to which information about health care processes reflects what people are likely to experience in practice (which is not always consistent with what is recognised to be 'best practice').

The omission of details from information materials sometimes leads to them being criticised as inaccurate and not comprehensive enough. However there is a balance to be struck between providing enough information to enable people to understand the main points and providing so much detail that understanding is hampered.

The concepts of 'honest' and 'unbiased' information are also useful to consider when thinking about the accuracy of information materials.

Accessibility, comprehensibility and acceptability of information

Information is of little use to people if they cannot get hold of it when they need it or cannot understand it when they have it. Factors that affect the accessibility, comprehensibility and acceptability of information include the language and images used to convey information, the media and presentation format used, and the ways in which information materials are distributed.

People vary in their communication needs and preferences. Information materials that are accessible, comprehensible and acceptable to some people will

not be accessible, comprehensible and acceptable to all. It is likely that a range of information materials will be required to meet the needs of people:

- from diverse cultural backgrounds;
- who communicate using different languages;
- who are hearing and/or visually impaired;
- who have other physical disabilities or limiting illnesses that impair their ability to access information in particular formats;
- who have learning difficulties;
- who have cognitive and/or emotional difficulties that affect their ability to process information;
- whose age, gender, cultural background, sexual orientation, social circumstances, disability or illness might affect their response to particular items of information and/or the way they are presented;
- who 'prefer' more or less detailed information about particular health issues.

Assessments of information and plans to develop or revise information materials should take into account the requirements of the Disability Discrimination Act (1995) and the commitments made in the Scottish Executive Health Department's policy document, 'Fair for all'.

The Disability Discrimination Act introduced new measures designed to end the discrimination that many disabled people have faced, particularly in terms of their ability to access services. The accessibility of information provided about and by health services falls within the terms of this Act.

The Scottish Executive is committed to ensure that NHS Scotland is 'Fair for all' in all aspects of its service provision. The recognition that 'Everyone is entitled to fair access to health care and the right to opportunities for better health' applies to the information provision aspects of health care and the opportunities that good quality health information offers. The development of a culturally competent NHS requires that information producers and providers are sensitive to the various meanings that particular words, symbols and images may have and the responses they may evoke in different people.

Information for patient-focused health services

Information materials about health and health care interventions may have a variety of purposes. We suggest that 'good' information materials have the potential to enable people to participate appropriately in their health care. Depending on their focus and aims, they might for example, help people to engage in an informed way in discussions with health care professionals, to get involved in decisions about their care, and to take medicines in ways that are safe, effective and appropriate to their lifestyles.

Information materials that are distributed via NHS Scotland should be consistent with the goals of a patient-focused health service. They should, for example, recognise and respect people's aspirations to be treated as individuals and to be able to participate appropriately in their health care.

Fitness for purpose

Obviously information materials should be well designed to meet their particular aims. For example, leaflets that aim to help people with a specific health condition choose between several different possible treatments should provide information that enables them to make comparisons between those treatments. Leaflets that aim to support informed consent should be consistent with current guidance about that.

It is unrealistic to expect one particular information package to cover all aspects of a health condition or health care intervention in a way that is appropriate for all people who are affected by that condition or who might be offered that intervention. An information package that is not 'comprehensive' in its coverage of a health condition or intervention can still be very useful to people – especially if it is provided as one of a series of materials that between them cover the full range of relevant topics and issues.

Helping people to identify further sources of information and support

No single health information package will answer all the questions that anybody ever has on a particular topic. However, it is reasonable to expect that information packages will address the questions that people most commonly ask about the topics they focus on, and that they will help people to identify further sources of information and support.

Helping people to judge the quality of information

Various factors affect the credibility of information for different people. However, there are several basic features that can help people judge whether the information is likely to be up-to-date and accurate. Information materials should indicate who was responsible for their production, explain what sources were used to compile them, and be clearly marked with production and revision dates.

What makes for good quality information provision?

Information provision is an integral part of good quality health care. Health care professionals can make a significant positive difference to people's experiences of illnesses and of health services by offering good quality, relevant information in a caring way at an appropriate time. The provision of inadequate, inaccurate, out-of-date or insensitive information may have adverse consequences for patients and may result in negligence claims against information producers and providers.

Health care providers can use well-developed policies and systems to enhance the quality of information provision (and particularly the distribution of information materials) to service users. The Clinical Negligence and Other Risks Indemnity Scheme (CNORIS) includes a risk management standard that relates to the provision of information to patients about the risks and benefits of proposed treatments or investigations. This standard encourages health care providers to reduce their risk by, for example, having a structured and regulated framework for the provision of patient information about the risks and benefits of the most common treatments, and having a policy for the composition and format of literature produced by the organisation.

Policies and systems relating to the provision of health information materials should be based on careful assessments of information need and the identification of good quality information materials. The following steps should help you to decide which information materials should be offered to whom and when:

- Identify the points along care pathways at which people are likely to have particular information needs.
- Consider which information needs require information materials to complement information offered by health care staff during one-to-one interactions.
- Identify any information materials that exist that might meet those needs.
- Appraise the information materials and decide whether and for whom they are appropriate.
- If there are currently no suitable information materials available to meet an identified need, check to see whether any are currently in production...
- ...If not, consider developing new materials and/or liaising with established information producers to do so.

Policies and systems need to be locally appropriate, but should ideally cover or help to achieve the following:

- The development and maintenance of clear, written statements for each care pathway that describe which information materials should be offered (as a minimum) to whom and when.
- An understanding among staff about why good information provision is an important part of good quality health care.

- Clarity among staff about who is responsible for offering which information materials to whom and when.
- Availability of an adequate supply of the required information materials.
- The easy incorporation of information provision into routine clinical practices.
- A routine means of checking that people have received or been offered the appropriate materials and correcting the situation quickly if they have not.
- An easy means by which staff can routinely record details of the information materials they have provided in patients' notes.
- Periodic reviews to check that all materials are still up to date. (A system for reviewing materials is likely to be based around a well-maintained register that includes details of the production dates, version numbers, authors/producers, suppliers and proposed review dates of all materials.)

Further advice about the development of document control policies and systems can be obtained from the Clinical Negligence and Other Risks Indemnity Scheme (CNORIS).

Part II

**Producing
good quality
information materials**

Before you commit yourself:

It takes a lot of resources, skills and time to develop good quality information materials so you should think carefully before you commit yourself to producing a new information package.

There are many health topics for which a number of good information materials already exist. If you are planning to develop a new information package your focus should be on:

- Important health topics that are not already covered by existing information materials; or
- Important health topics for which only poor quality information materials exist; or
- The needs of people who are not well served by the available range of materials.

If you are not sure what is required, a quick read through the rest of this guide should give you a better feel for the various tasks/stages that are involved.

Initial thoughts about developing information materials

If you are thinking of developing an information package, the following questions should help you to think through what you are trying to achieve and whether and how you should proceed.

- What are you thinking of producing?
 - Who is the information for?
 - What do you want it to achieve?
 - What information will be included?
 - How will people access and use the information?
- Do people want or need the kind of package you envisage?
- Does a suitable information package already exist?
- Do you have the necessary skills and resources?

What are you thinking of producing?

The questions of 'Who is the information for?', 'What do you want it to achieve?', and 'What information will be included?' are all inter-related. Examples of the kind of stage you might want to reach in your 'initial' thinking are given in the boxes.

Initial thoughts about a leaflet about anti-epileptic medication

We propose to develop a leaflet for people with well-controlled epilepsy about the option of withdrawal from anti-epileptic medication. We want the leaflet to explain that coming off anti-epileptic medication might be an option for people with well-controlled epilepsy; summarise the research evidence about the effects of withdrawing from anti-epileptic medication; outline the potential advantages and disadvantages of continuing or discontinuing anti-epileptic medication; identify issues that people might want to consider before making a decision; and support discussions between health care professionals and people with well-controlled epilepsy about the option of withdrawal from anti-epileptic medication.

You also need to consider the media in which your information package might be produced and the routes by which people will access it.

Factors to consider when deciding which media to use for a health information package include:

- The potential of different media to convey particular types of information
For example, video is very useful for showing interviews with people who have experienced a particular condition or intervention, presenting role models of patients asking questions in consultations, or demonstrating self-care procedures such as use of an injection pen.
- The abilities and resources that people need to be able to use the media
Some media such as audiotapes, videotapes and CD-ROMs can only be used by people who have access to the equipment needed to play them. Some media will be unsuitable for particular audiences. You need to think carefully about which groups your choice of media might exclude, and consider how else the information might be made available to them.
- The extent to which the media allow people to revisit, reuse and share information
It is important to consider the situations in which people might want to use or share information, and to think how well different media can meet their requirements. For example, leaflets can be read almost anywhere. People can flick through them quickly to find a section they want to read again, and can take them home to share with family members. In contrast, touch screen information points can only be used to their full potential in the places where they are sited.
- The cost of producing, reproducing, distributing and updating information packages in different media
It is easier to modify and update information in some media than others. You might want to consider how likely it is that your information will need frequent updating before selecting a media format.

Initial thoughts about a leaflet about barium swallow investigations

We propose to develop a leaflet for people who are scheduled to attend an outpatient clinic for a barium swallow investigation. The leaflet could be given to people by the doctors who recommend a barium swallow investigation and/or it could be sent out from the clinic with the letters that offer people appointment dates for their barium swallow investigations.

The leaflet is unlikely to be individually tailored to tell every person why a barium swallow examination has been recommended in their particular case, but we want it to outline the range of reasons why barium swallows are done and the types of problems that they can and cannot detect or rule out.

We want the leaflet to tell people how to prepare for the barium swallow so that when they attend the clinic they are adequately fasted. We want the leaflet to explain the procedure in an honest but reassuring manner so that they know what to expect when they get to the clinic and are not unduly anxious. We want the leaflet to prepare people for the discomfort they might experience and to explain the risks that are associated with the procedure in relation to the benefits. We want the leaflet to explain when, how and from whom they should expect to find out the results of the examination.

People might obtain health information materials from:

- Health care professionals directly involved in people's care (for example dentists, doctors, midwives, nurses, therapists)
- Health care venues (for example, clinic waiting rooms, patients' libraries, hospital health information points)
- Health information services (for example, NHS 24, Cancer BACUP)
- Self help groups and voluntary organizations
- Pharmacies, health food stores, supermarkets, high street health information points, public libraries, community centers
- The Internet

The appropriateness of these different outlets depends in part on the aims, intended audience and content of your information package. For example information about self-treatment for minor illnesses might usefully be made available via pharmacies, primary care clinic waiting rooms and public libraries. In contrast, information about post-operative care and recovery is probably most appropriately given to people before they go into hospital and/or during their hospital stay by the health care professionals who care for them.

It is useful to have a reasonable idea about how people will access an information package before you finalise your content. You need to consider the situations people will be in when they receive your information as you make decisions about what information to present and how.

Do people want or need information on this topic?

Before you invest a lot of time and effort in developing an information package you should establish that your intended audience actually want or need information on the topic you plan to address. You might already have evidence that people want this information if, for example you know patients have been asking health care professionals or health information services for it. You might have read newsletters produced by patient groups or research papers that tell you that patients, their families or members of the public have identified the information as important. You might know that people are highly appreciative of information materials that provide similar types of information about other health conditions or treatments. If you do not have such evidence, you could check with health care professionals, patient representatives and members of your intended audience.

If you are planning to approach members of your intended audience to find out whether they want particular types of information, it is important to recognise that people may not be able to spontaneously identify all the kinds of information they might want. They may not know what information is available. In addition to asking them about the types of information they want, you could show them examples of the kinds of information that might be included in an information package and ask how important or useful they think this information would be.

Does a suitable package already exist?

You could check the following sources to identify any existing information materials on your chosen topic:

- Your own organization (ask the patient information officer if you have one, or the designated director for patient and public involvement at your Health Board)
- NHS Health Scotland (maintains a database of patient information leaflets)
- NHS 24 (maintains a stock of information materials that can be given to callers if appropriate)
- Voluntary sector organizations that focus on your topic of interest and/or serve the people who comprise your intended audience
- Royal Colleges or other professional bodies that cover your topic of interest
- The Internet
- The Involving People team at the Scottish Executive Health Department. (As we write in June 2003 the team are considering the possibility of establishing a register of quality assured information materials).

If you do identify information materials on the topic you are interested in, you will need to assess their quality and suitability for particular groups of people before you decide whether to develop new materials or revise or adapt existing ones. The quality criteria you might consider were outlined in '*What makes for good quality health information?*' (page 3).

Do you have the necessary skills and resources?

A range of expertise and skills are needed to produce good quality information materials, so it should usually be a team effort. We suggest you check that you will have access to all the expertise, skills and resources you will need before you commit yourself to producing an information package.

Some of the things you will need to be able to do and budget for include:

- Clarify the information needs, current knowledge and beliefs of the intended audience
- Familiarise yourself with the context(s) in which the information will be used
- Locate appropriate information sources, including sources of research-based information about the effects of health care interventions.
- Critically appraise the available information and extract relevant details
- Communicate the relevant information clearly using appropriate languages and images
- Work effectively with a variety of people including members of your intended audience, health care professionals and media production specialists.

When thinking about the composition of an information production team, you might consider:

- Whose perspectives, knowledge and skills will help ensure you develop a high quality package?
- Whose involvement might affect the credibility and future use of the package?

You do not need to have every type of expertise and skill among the core team, because you can 'buy in' certain types of advice and input on a consultancy-type basis. However, a core team that includes the following is probably a strong starting point:

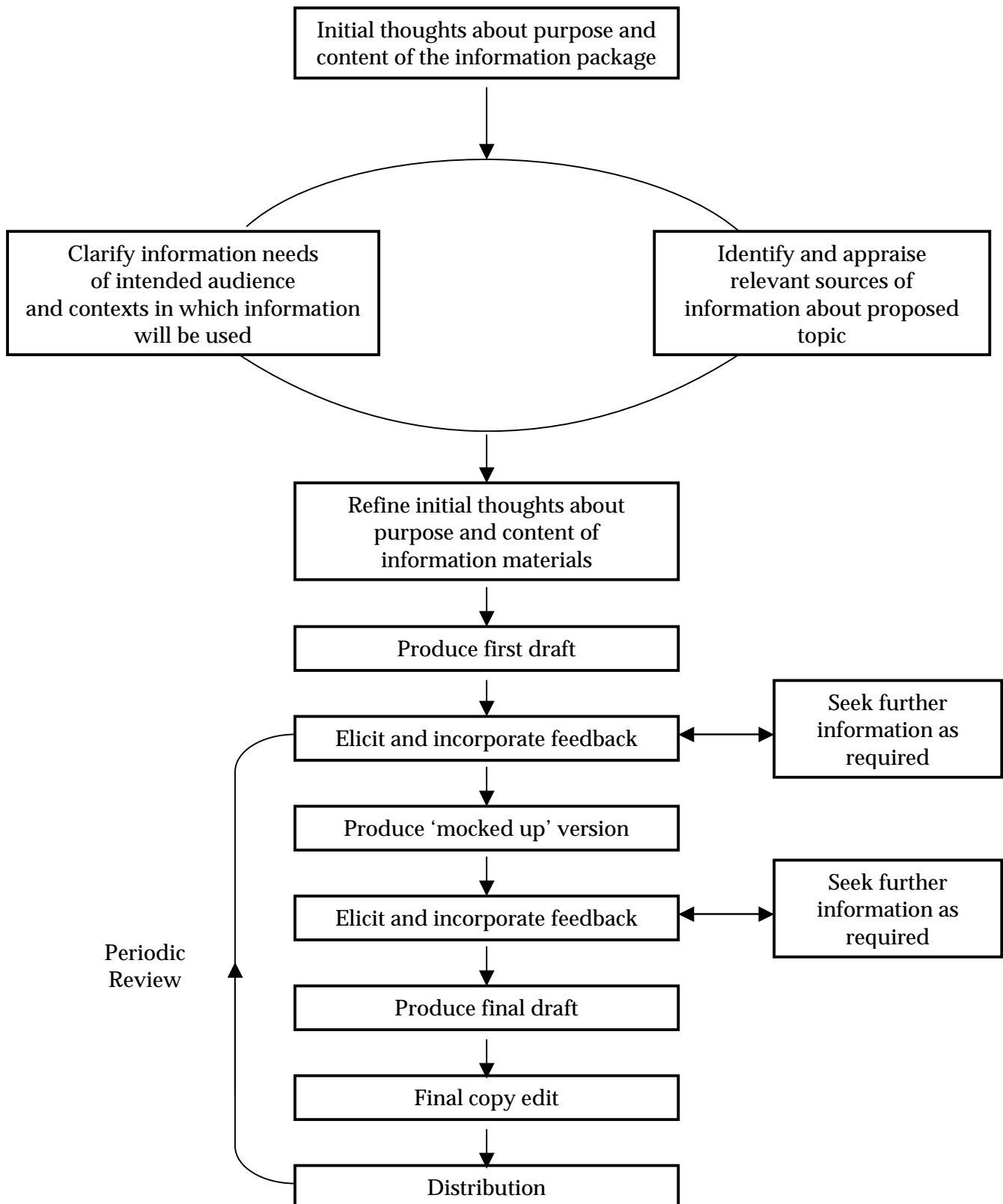
- Relevant information searching, research and critical appraisal skills;
- Appropriate information handling, communication and basic media production skills
- Relevant clinical knowledge and experience
- Personal experience of the health condition and/or health care interventions of interest or of working as representatives of people with such experience.

If you decide to proceed...

If you decide that you want either to develop an information package from scratch or to revise an existing information package, we suggest that you continue to read through this guide before you get started, then refer back to the relevant sections as you proceed.

An overview of the production process

The following figure outlines the main stages of our approach to the development of written information materials. It assumes you have already checked that there is not already a good quality information package that serves the purpose you envisage.



Informing the content of information materials

You will need to identify several different types of information before producing a first draft. In addition to the information about the health condition(s) and/or health care intervention(s) that will be included in your package, you will need background information to help inform the way you present this. In this section we consider some of the types of background information that you might need about your audience and the contexts in which your information package will be used.

Information about your audience

What do people want to know?

If your information package is going to be useful, it must provide the kinds of information that people need and want. It is important to check out how well your initial thoughts about what information will be included in your package correspond with the types of information that your audience wants. Even if you are trying to help people to adopt a particular behaviour (such as stopping smoking or accepting vaccination) you are most likely to succeed if you find out what issues matter to people in relation to these behaviours.

Some of the types of information that people might want are listed in the box below.

People might want information about:

- What causes a condition
- The symptoms, signs and problems associated with a particular condition
- Why and how screening and diagnostic tests are done and what the results might mean
- What forms of care are recommended for people with a particular condition
- Which treatments might help them
- What the treatments involve, how they are likely to help and what kinds of risks they entail
- What the effects of having no treatment would be
- What kinds of prognoses are associated with particular conditions and interventions
- Which symptoms need urgent attention
- How health care for people with their condition is usually organised
- What they might experience during and after episodes of care
- What other people have felt like and how they have coped with particular conditions and treatments
- How a condition or treatment might affect their daily life
- How to help themselves and their families
- What kinds of help they might get when, from whom and how

What do people already know and believe?

You will be better able to produce information that is relevant to your intended audience if you take the trouble to find out what they currently know or believe. It is quite likely that they hold a range of understandings and perceptions. If the information you provide is to be useful, they will need to be able to relate it to these understandings and perceptions. If you identify any commonly held misconceptions, you will be able to address these directly in the information that you provide, as the examples in the box illustrate.

Example 1

When developing an information leaflet about wisdom teeth removal we spoke to dental health care professionals and people who had consulted them about their wisdom teeth. From our discussions we learnt that most dental health care professionals had adopted recent guidelines and were no longer routinely removing impacted wisdom teeth. However many people still thought that most wisdom teeth would need to be removed. These discussions suggested that the leaflet should address the mismatch between what was happening in clinical practice and what people thought should be happening. In the leaflet we explained that not all wisdom teeth cause problems and not all wisdom teeth have to be removed.

Example 2

A team that was developing information leaflets for people with cataracts held focus group discussions with people who had cataracts. While talking about surgery, they found that many of these (mainly older) people remembered bad experiences with anaesthesia. Having identified this common worry, the team was able to include a statement in the leaflet that tried to reassure people that modern anaesthetics were safer and had fewer side effects than older ones. The focus group discussions also revealed beliefs such as 'a cataract has to be ripe before it can be removed'. These were addressed in a section in the leaflet called 'myths you may have heard'. (Source: Entwistle VA et al, 1998).

Information about the context(s) in which the information will be used

You are more likely to be able to develop relevant and useful information materials if you are aware of the context(s) in which the materials will be used. You may need to consider: what information people are currently given; relevant guidelines, standards and policies; and how care is organised and delivered.

What information is currently given to people?

It can be helpful to know what kinds of information are currently given to members of your intended audience. This can help you decide what information you need to include and how your information package will 'fit in' to the overall pattern of information provision for these people.

Health care professionals are an important source of information for many people. You need to know what information health care professionals usually give to your intended audience (either during spoken conversations or via information materials), and whether the information you plan to provide is consistent with this. If you are thinking of advising people that they can ask their health care professionals about particular issues, you need to be reasonably confident that their health care professionals will be able to provide up-to-date and accurate information and good advice about those issues. If there are differences of opinion amongst health care professionals about the health condition or intervention that you are writing about, you need to consider whether and how to address these in the information you provide.

Voluntary organizations also provide a lot of information about health issues. It is worth checking what views they disseminate about the health conditions and health care interventions that you are planning to write about.

More generally, it will be useful as you develop your own materials to be aware of any views that are expressed about your topic in the public domain.

Relevant guidelines, standards and policies

You need to be aware of the recommended norms for the management of the health conditions and the use of the health care interventions that you are interested in. If, for example, a policy decision has been taken that access to a particular intervention will only be available to people who meet particular criteria, you will need to consider how to address this in your information package.

If you are developing information materials for use in NHS Scotland, you should check whether either of the following organizations have addressed relevant topics:

- Scottish Intercollegiate Guidelines Network (SIGN) (issues clinical practice guidelines)
- NHS Quality Improvement Scotland (issues advice about the use of particular health technologies and sets and monitors standards of care for people with particular health conditions).

Sometimes it may be appropriate to describe and reference these` guidelines, standards and policies explicitly in the information you provide. At other times you will need to take them into account as you present related information.

Organization and delivery of health care

Patterns of practice may vary across localities and health care settings. Awareness of these variations and of any reasons for them is particularly important if you are producing information materials that are to be widely used. For example, it may be inappropriate to use a phrase such as ‘Your doctor will

carry out tests A, B and C' if there is a great deal of variability in terms of which tests doctors carry out.

If you are developing information materials for use throughout NHS Scotland, you need to give particular consideration to patterns of care for people living in remote or rural areas, including the Islands. If you are discussing treatments that are only available in specialist centres, it might be important to alert people to the possibility that they may not be available locally.

Awareness of the way health care is organized and delivered to members of your intended audience will also be important for your thinking about the distribution of your information materials.

Finding the different types of information you need

Your project team may have a lot of knowledge and expertise relating to your topic of interest. However, you are still likely to need to use a variety of information sources during the development of your information materials. We highlight a few of these here. References and contact details are provided at the end of the guide.

Research evidence about people's experiences and views of health conditions and health care interventions

Social and psychological studies of people's experiences and views of health conditions and health care interventions can help you get a feel for the kinds of issues that are likely to be important to your intended audience.

However you need to look carefully at the relevance of the research for your particular audience and for the contexts in which your information materials will be used. When considering research evidence about people's experiences and views, you might usefully ask:

- How similar are the people who were studied to your intended audience?
- Are the health care interventions experienced by the people who were studied similar to those covered by your information?
- Is the context in which the research was carried out similar to the context in which your information package will be used?
- How were people's views elicited and how might this have affected the responses obtained?

The Database of Individual Patient Experiences (DIPEX) is a particularly useful multimedia source of information about people's experiences of health conditions and treatments, although it currently only covers a limited range of topics. Its producers use rigorous interview techniques and are careful to include people with a range of experiences. DIPEX may be a useful source of information for you as you develop your information materials. It might also be a resource that you want to refer people to for further information.

Research evidence about health conditions and health care interventions

Epidemiological studies can provide you with information about what causes particular health conditions and how many people with what kinds of characteristics have particular health conditions.

Systematic reviews of research evidence are usually very good starting points for information about the effects of health care interventions. Systematic reviews aim to provide clear and unbiased summaries of the best research evidence that is available to answer specific questions about the outcomes of particular interventions. They usually provide more robust information than single

research studies. However you still need to consider the quality of the evidence they provide and the extent to which the evidence applies to your particular audience.

We have included a list of the main sources of systematic reviews and journals that publish critical appraisals of good quality systematic reviews and randomized controlled trials in the reference list at the end of the guide.

Clinical practice guidelines and standards documents

Research evidence about the effects of health care interventions is increasingly used in the development of clinical practice guidelines, treatment protocols, and service standards. Several key organizations now issue guidance about the treatment of particular conditions or the use of particular interventions.

Within Scotland, the Scottish Intercollegiate Guidelines Network (SIGN) produces guidelines for clinicians outlining recommended procedures for a range of conditions and situations. NHS Quality Improvement Scotland issues advice to Health Boards and health care professionals about specific health care interventions. It also issues good practice statements, defines standards for clinical services and assesses the performance of services throughout NHS Scotland against these standards.

Information about patterns of practice

Audits can provide you with information about patterns of health care practice and the extent to which standards of good practice are met.

Within Scotland, the Information and Statistics Division can give you up to date information about various aspects of health service activity, including the numbers of particular types of operation performed per year or of particular types of drug prescribed.

Health coverage in the popular media

Media coverage of the health conditions and health care interventions that are to be the focus of your patient information materials can help you identify any complementary and/or conflicting messages about the topics of interest that have been aired in the public domain.

A quick check of the most accessible newspaper databases or press cutting services is likely to be particularly useful if the health conditions and/or health care interventions that you are interested in are controversial or topical. Searches of the media that identify few relevant items can still be useful in that they might indicate that public awareness of the topic is limited.

Autobiographical accounts of illness and health care experiences are often available in book form, in magazine articles or on the World Wide Web. These may be useful, but you need to be aware that the experiences and views reported might be highly 'atypical' and thus potentially misleading if they are not set in the context of the more usual range of experiences and views.

Voluntary organizations

Voluntary organizations can be very useful to information producers. Their officers, meetings and publications can usually offer very good insights into the kinds of issues that are important to people with a particular health condition, and they may be a useful source of personal accounts of what it is like to live with a condition. However, they may represent only a sub-sample of an overall group of people with a particular health condition.

NHS 24, NHS Health Scotland and Voluntary Health Scotland can help you to identify national and local voluntary organizations and groups with interests in particular conditions or issues.

Members of your intended audience

Even if you have patient representatives on your project team, well planned discussions with individuals or groups of people who would be among your intended audience can provide you with useful information (and confirmation or disconfirmation of your previous thoughts) about, for example:

- the range of experiences people may have of a health condition, intervention or health service
- the knowledge, beliefs and attitudes people hold
- the types of things people are concerned about
- the types of information people would like
- the kinds of responses people might have to the information you are planning to present.

Discussions with members of your intended audience could take place at various stages during the development of your information materials and might take various forms. You need to think carefully about how you will identify and approach people, and about how you organise your discussions and phrase your questions.

Identifying and approaching people

Data protection legislation and guidelines about confidentiality place restrictions on the methods you may use to identify and contact people who have a particular health condition, have received a particular intervention or used a particular service. The Confidentiality and Security Advisory Group for Scotland (CSAGS) issues guidance about this.

You might consider advertising for volunteers or asking relevant health care professionals to ask people if they would be willing to help with the development of an information package. Voluntary organizations might also be willing to identify and approach relevant people from among their members.

Depending on the nature of your project and the methods you plan to use to approach and involve people, you might need to obtain approval from an appropriate ethics committee before you proceed.

Discussion techniques

Discussions with members of the intended audience may be on an individual basis or in a group and may be more or less formal, structured and detailed. A variety of techniques are described in the *Building Strong Foundations* toolkit that offers practical guidance on various approaches to involving people in the NHS.

You need to think how your respondents are likely to perceive you (or the designated interviewer) and the purpose of the discussion. Their perceptions can affect the kinds of information they give you, so the way you introduce yourself and the project, and the way you ask questions, needs careful consideration.

In discussions with members of your intended audience it is important to recognise that people might not know what kinds of information it would be possible to have. In addition to asking what they would like to know, you could show them examples of the types of information that might be included in an information package and ask how important or useful they think these would be. You might also want to explore what they understand by the information provided and how it makes them feel.

Health care professionals

Even if you have one or two health care professionals on your project team, discussions with others can be extremely useful, for example to give you a better understanding of:

- the kinds of information that health care professionals with different backgrounds and levels of experience think is important to communicate to people with particular health conditions who are considering or facing particular health care interventions,
- the ways in which health care professionals describe and discuss health conditions with patients in practice
- the ways in which health care professionals offer and deliver health care interventions
- the processes that people might go through during episodes of care for a particular health condition

It may be important to talk with several different types of health care professionals because they may focus on different aspects of health conditions

and interventions, and may have different perspectives on these. For example, if you are planning to provide information about a surgical procedure, you might want to ask clinic and ward administrators to describe how referral procedures work and how 'the system' communicates with patients, anaesthetists how they discuss and deliver anaesthesia and pain relief, surgeons about what particular operations involve, and nurses and therapists about post-operative care.

Health care professionals' willingness to contribute to discussions about the content of a new information package may depend to a large extent on their working situation. Some health care professionals may prefer to take part in individual discussions at their place of work, while others may enjoy opportunities to meet with their peers for group discussions. Some professional groups might be willing to discuss issues relating to the production of information materials for patients during team or special interest meetings.

Producing a first draft

By the time you get to the stage of producing a first draft, you will have clarified the aims, intended audience, main content areas and media format for your information package. You will be familiar with the context(s) in which your information package will be used, and will have obtained most of the source information that you need.

The next step is to think how you want to organise the information and what kind of 'tone' you want to set. Then you can start writing!

The person who produces the first draft will ideally have excellent writing skills and experience of writing for 'lay' audiences. Although the draft is likely to be revised several times, you should aim from the outset to write clearly to an agreed initial structure. Your written English will be easier for people to read and understand if you use:

- A logical order to present the information
- Section headings;
- Short words where possible,
- Explanations for important medical terms
- 'Active' rather than passive verbs (e.g. 'the nurse will give you...' rather than 'you will be given...'),
- Short, simple sentences
- Bullet points or numbered lists when you need to make several points under one heading.

A number of organizations and resources offer useful advice about writing clearly in English for lay audiences. We have listed some of the main ones at the end of the guide.

In this section we focus on ways you can make your information materials more useful and acceptable to your intended audience. We also discuss some of the key issues relating to the presentation of research evidence about the effects of health care interventions.

Ways of making your information materials more useful and acceptable

A clear statement of aims

People will be better able to judge whether an information package is likely to meet their needs if it includes a clear statement of what it aims to achieve, what it does and does not cover, whom it is intended for, and (if necessary) to whom it does not apply. An example is given in the box.

If you are preparing information about sensitive topics, it might be more appropriate to state the aims of the information package in an introductory section rather than on the front cover.

Communicating the aims of an information leaflet about anti-epileptic medication

An NHS Scotland leaflet for people with well-controlled epilepsy about the possibility of withdrawing from anti-epileptic medication was developed for distribution via GPs, hospitals, pharmacies and epilepsy organizations.

The title on the front cover was: 'Anti-epileptic drugs – are they for life?'

A section at the beginning of the leaflet, titled 'Who is this leaflet for?' explained more fully who the leaflet was for, who it didn't apply to and what it didn't cover:

'This leaflet is for adults with epilepsy who are taking anti-epileptic drugs and have not had a seizure for two or more years. It describes what current research says about staying on, or coming off, anti-epileptic drugs. People with epilepsy have different opinions about their anti-epileptic drugs. This leaflet gives you information to help you make the choices that are right for you.

If you have juvenile myoclonic epilepsy, most of the information in this leaflet will not apply to you. People with juvenile myoclonic epilepsy should usually keep taking their anti-epileptic drugs because they are very likely to have more seizures if they stop.

Women who are, or who might become, pregnant and are considering coming off their anti-epileptic drugs, will need to consider other issues that we do not cover in this leaflet. (You can discuss what is best for you and your baby with a doctor or nurse who specialises in epilepsy care.)'

Information about further sources of support and help

A single information package is unlikely to answer all the questions that anybody will ever have on a particular topic. You can help people to fill any 'gaps' in the information you provide by letting them know where they can look for further information, support or help. You might consider providing brief details of:

- The sources you used to prepare your information package; (If you can't include a full reference list of sources you can let people know where they can obtain this information from if they require it.)
- Good sources of more detailed information;
- Good sources of information on related topics; and
- Organizations that provide information, opportunities to contact other people in similar situations, practical help with day-to-day matters and other forms of support.

You might want to check what kinds of help organizations can offer and to whom before you mention them. You should let people know if some self-help groups and voluntary organizations have strong preferences for particular treatments.

It is also advisable to let organizations know that they will be mentioned in information materials so they can prepare to respond to any enquiries.

Issues relating to language

It is obviously important to avoid using unnecessary jargon. However, people will often hear the health care professionals who care for them use technical medical terms, and they may find it helpful to have these terms presented, spelt out phonetically and explained in health information materials.

The ‘tone’ of information materials can make a big contribution to how people respond to them and how useful they find them. Your information package is more likely to be helpful and acceptable if you talk to people in a way that is honest but constructive, respects their capabilities and encourages them to help themselves without overburdening them with implied responsibilities. The table below summarises the kinds of terms that people with a range of health conditions used to describe what they liked and disliked about the language used in information materials about those conditions and their treatments.

| | Liked | Disliked |
|---------------------------------|--|--|
| Tone/Mood | Positive, hopeful, encouraging, cheerful, optimistic, reassuring, constructive, non-alarmist | Negative, off-putting, stresses all the things which could go wrong, alarmist |
| Tone/Stance | Honest, practical, down to earth, sympathetic, understanding, not condescending, doesn't talk down to you | Unrealistic, glosses over real problems, glosses over possible after effects, over-optimistic, misleading, disinterested, written by someone doing a job, patronising, talking down to me, childish, dismissive in tone, flippant, judgemental |
| Relating to the audience | Talks to you, relates to you personally, treats you as an individual, uses 'you' a lot, chatty, friendly, warm, womanly, human touch | Talks about patients not people, clinical, impersonal, cold, distant, too formal, sterile, remote, dry, like a tax form |

Source: Coulter A, Entwistle V, Gilbert D. *Informing patients: an assessment of the quality of patient information materials*. London: King's Fund, 1998

You need to think carefully about how ‘prescriptive’ your language should be in relation to different types of information, and what kinds of roles it implies patients should play. Phrases such as ‘you might prefer’, ‘you might choose’ implicitly permit people to have their own opinions and make their own decisions in ways that phrases such as ‘you should’ do not. Phrases such as ‘your doctor will decide’ may give the impression that patients have no say in decisions.

You also need to think about how to strike an appropriate ‘balance’ in the language that you use to provide information about prognoses with or without treatment. You need to avoid being either overly optimistic or overly pessimistic.

Communicating probabilities

Information about the effects of health care interventions usually involves probabilities. Information about probabilities is often difficult to understand, and different ways of presenting it can affect the way people interpret and use it. There is no clear consensus about the best ways to present probabilities. Our top tips are:

- Don't rely on verbal descriptions such as 'few', 'some' or 'many'. People imagine very different quantities or proportions when presented with such terms!
- Remember that many people find it difficult to understand decimal fractions (such as 0.05) and percentages (such as 5%). It is probably preferable to talk in terms of '5 out of every hundred people' (or '1 out of every twenty people') or to use diagrams (for example you could colour 1 out of twenty stick people a different colour).
- Be aware that the way you 'frame' a message can influence people's perceptions. For example, the decisions that people make about accepting chemotherapy for cancer can be influenced by whether they are given information about the outcomes of the treatment in a positive frame (information about the chances of surviving) or a negative frame (information about the chances of dying).
- If you are giving information about the effects of more than one health care intervention, try to present information about the different interventions in the same way so that people can easily compare them.

Making information accessible to people with special communication needs

People who do not understand or read English and people with sight or hearing impairments often find it particularly difficult to access the information they need. If you present information only in written English, some of the people who could benefit from it will find it difficult to access it. We encourage you to consider:

- Do you have the budget and the ability to produce several versions for people with different communication requirements?
- If not, which groups would benefit most from the development of an information package suitable to their needs?
- Could other organizations or groups work with your information and make it accessible to people who would otherwise struggle to use it?
- Are there other arrangements you can make to minimise the disadvantage to which people with special communication needs are put? For example, could the information be given to people while they have access to interpreters or advocates during outpatient visits or inpatient stays?

The production of information materials for people who do not read or speak English usually requires more than a simple translation of materials written in English. A broader cultural sensitivity is needed to ensure that the information will be relevant, useful and acceptable. Examples and illustrations might need to be revised as well as words.

Communicating research evidence about the effects of health care interventions

It is important that any information you provide about the effects (positive or negative) of health care interventions is based on and consistent with robust and relevant research evidence. However, research evidence can be presented in different ways and with a variety of effects. The inclusion of research evidence in health information materials, like the inclusion of any kind of information, will require judgements to be made about exactly what information should be presented, how, and in what kind of context. Your judgements should take into account the aims of your information package and what you know about your intended audience and the contexts in which the information will be used.

You may encounter a number of issues and problems as you strive to ensure that the information you provide about the effects of health care interventions addresses patients' questions and is consistent with the best available research evidence. We consider some common ones here:

A lack of research evidence or lack of clear answers from research evidence

Some of the questions that patients want answers to have not been addressed by research or cannot be answered clearly by the available evidence. In these circumstances there is growing consensus that it is best to be honest about gaps in research evidence.

Imagine, for example, that you are providing information to help people choose between different treatment options for a particular health condition. Two of the treatment options have been quite thoroughly studied, but there is very little research evidence about the effects of the third option, which is relatively new. If you decide to present information about the first two options only, people who have heard of the third option may be frustrated to find that it is not covered. They may assume either that your information is out of date or that the new treatment is better. If they assume that the new treatment is better, they may think that you (the information producer) are trying to 'fob them off' with the other (older, cheaper and what they might assume to be less effective) treatments. If you mention the third treatment and explain that nobody knows for sure how effective it is or what risks it may have because it has not yet been thoroughly researched, people may be less likely to jump to premature conclusions about its superiority.

Often, the available research evidence does not warrant a confident conclusion about the effects of a treatment. For example a systematic review might conclude that there is not enough evidence to allow us to be sure that there is any difference between the effects of two treatments, or that we can be 95% confident that the cure rate of an intervention lies somewhere between 20% and 80%.

Glossing over or ignoring uncertainty can be deceptive. There are ways of communicating uncertainty without confusing people. For example, you might consider:

- Qualifying statistics with words such as ‘about’, ‘roughly’, ‘approximately’ or ‘on average’
- Presenting a range, such as ‘between 2 and 8 out of every ten people who are treated...’
- Giving an upper or a lower bound, such as ‘up to 8 out of every ten’

If there is no good research evidence about the effects of particular treatments, you need to look for the best available evidence and reasonable estimates and opinions. If you do need to use estimates and opinions, you should make it clear that this is what you are doing. For example, you might say that:

‘Some doctors think that the treatment will cure 8 out of every ten people who receive it. Other doctors think that it will only cure 2 out of every ten. No research has yet been done that can tell us reliably which doctors are right.’

Uncertainty about who will benefit

Sometimes, research evidence consistently shows that a certain proportion (say 90%) of people who are given a certain treatment have a particular outcome (for example, resolution of their symptoms). However, no one can tell whether a particular person will be one of the 90% or one of the 10%. You can indicate this type of uncertainty with statements such as

‘Nine out of every ten people will find that their symptoms clear up with this treatment. However, it is difficult to tell exactly who will benefit from the treatment.’

The contested importance or usefulness of the research evidence

In some situations the importance of research evidence is contested. For example people might disagree about which likely benefits and possible harms should be mentioned in connection with any treatment option and how much detail should be given. Some of these disagreements may reflect considerations other than the usefulness of the information to patients. For example, pharmaceutical companies might secure some legal safeguards by giving patients long lists of all the possible side effects of their drugs, and the content of the Patient Information Leaflets that are included within pharmacy packs of medicines is highly regulated.

Health care professionals also need to warn people of the possible risks of health care interventions in order to satisfy insurance and risk management requirements. Long lists of possible adverse effects are not very useful to patients (and indeed may be extremely off-putting) unless they are accompanied by some indication of the likelihood of the side-effects occurring, persisting, being severe, and being reversible. Ideally, you are looking to find ways of

fulfilling legal requirements and at the same time providing information that is relevant and not unduly alarming to patients.

If you are not sure whether to include information about particular benefits and harms, we suggest that you should try to find out what members of your intended audience think, and give fair weight to their views. If you decide not to include details of all possible adverse effects in your information package, you could usefully let people know that further information is available and suggest how they might obtain it if they want it.

The disputed applicability of the research evidence

The applicability of research evidence to particular groups of people may be unclear and is often disputed. Even if the applicability of research evidence is relatively clear, it may not correspond precisely with the range of people and situations for whom your information is intended.

We suggest that you should try to indicate as clearly as possible to whom your information package and particular items of information within it do and do not apply. You might identify factors that are thought to affect the applicability of information about the effectiveness of interventions (for example, is a drug likely to be less effective among people with a co-morbid condition or who have responded poorly to another drug). You might also indicate if there are uncertainties or differences of professional opinion about the effectiveness of a treatment for people with particular characteristics.

What about interventions that might not be available?

Some health care interventions are not offered by NHS Scotland. This raises the question of whether information packages should mention all possible health care interventions or only those that are widely available.

Again, honesty is the best policy. We recommend that you cover all the relevant health care interventions in your information package but explain clearly why some might not always be available. It is particularly important to give clear explanations if research evidence has shown some interventions to be less effective than others. Documents such as the advice issued by NHS Quality Improvement Scotland are likely to be particularly useful in such circumstances.

People may experience and express dissatisfaction if they feel they are being denied access to health care interventions that they think they would benefit from. However, there is more chance of an open debate if people have access to the relevant information. Also, in some situations, the pressure of public demand might be seen as ‘a good thing’.

Eliciting and incorporating feedback on drafts

Once you have prepared your first draft, you need to work on improving it. The usual way to do this is to ask other people to comment on your first and subsequent drafts.

Whose opinions should be sought?

As a first step, we suggest that members of your project team review the first draft to check that all the main content areas that were agreed have been covered, that the text seems relatively easy to read and that the 'tone' seems appropriate.

Once you have addressed any initial concerns of your project team, you can ask other people with relevant expertise to comment on the draft and make suggestions about how it might be improved. It is important to do this because it is often harder to see the shortcomings in your own work than in someone else's, and if you only seek comments from members of your own team your information package will only benefit from a limited range of perspectives and skills.

There is no real substitute for asking members of your intended audience to look at your draft and tell you whether they understand it, whether they think it covers all the important (relevant) issues, whether the tone and style is acceptable, and how they think it could be improved. As with all health service developments, input from health service users is extremely important for the development of information materials.

Other people you should consider asking include:

- Clinicians, academics or researchers who have particular research-based expertise
These people are likely to be particularly well placed to comment on whether the information presented reflects the best available research evidence about the effects of interventions.
- Patients' representatives or staff from relevant voluntary organizations
These people are likely to be particularly well placed to comment on whether the information reflects the range of experiences of people who live with particular conditions and/or have received the interventions of interest. They might also have useful suggestions about how the information might be made more acceptable and useful to its intended audience.
- Relevant health care professionals
- People who work with members of the intended audience and deliver the types of interventions covered in the information are likely to be particularly well placed to comment on the extent to which the information is relevant to the context(s) in which it will be used and how well it reflects current practice.

- People with expertise in information presentation or communication
Journalists, the Plain English Campaign and graphic designers are among the people who should be able to help you to communicate your message more clearly and effectively to your intended audience. If you are using minority languages, communication symbols, or special formats, consult people who are experienced users of these.

It is probably worth asking for comments from several people within each category. In terms of members of the intended audience, try to include people from different social backgrounds and with varying experiences of the health condition and/or health care interventions of interest.

If you know that some of the people you are thinking about consulting have strongly held views about particular topics, you might consider trying to identify people with opposing views so that you can see the range of ways in which your information might be received. If you know that several different types of health care professional work with members of your intended audience, try to ensure you get some feedback from members of each.

How should opinions be sought?

There are various ways in which you can ask people to comment on drafts. You need to think carefully about which approaches are most likely to enable them to draw on their particular types of expertise and insight, and feedback honestly and constructively to you at minimum inconvenience to them. It might be appropriate to use different approaches to elicit the opinions of different groups of people. For some approaches you might need to obtain approval from an ethics committee.

When seeking the views of members of your intended audience, you might consider the following points:

- Many people are not used to writing down their comments and opinions. Some have literacy problems.
- Group discussions may be more productive than postal requests for comments as they allow people to compare and contrast views, to develop critical ideas and to work together to identify areas of improvement.
- People may be reluctant to criticise an information package to someone who has been responsible for developing it. You may get more honest feedback if you invite people to talk to someone outside the team and clearly state that you would welcome comments to help you improve the package.
- 'Open' comments from a few people who have a variety of backgrounds and experiences might be of more use to you as you seek to improve your draft than 'closed' responses to structured questions from hundreds of respondents.

One way of asking for feedback is to send people a copy of your draft and ask them for written comments and suggestions about how it might be improved. Alternatively you could give people a copy and ask them to discuss it either individually or in a focus group.

You might ask specific questions about how to improve particular aspects or parts of your information package. For example:

- Were there any sections or bits of information that you had to read twice because they were hard to understand? If yes, please list them.
- Which sections or bits of information did you find useful? Can you explain why?
- Which sections or bits of information did you think were not very useful? Can you explain why?
- Can you think of any other topics that you would like the leaflet to cover? If yes, please describe them.

Other types of issues you might ask people to comment on include:

- The clarity of the aims of the information package
- How well the information package achieves its aims
- Whether the information provided was likely to be relevant, and to address the questions that the intended audience want answers to
- Whether there are any inaccuracies in the information provided
- Whether important areas of uncertainty were appropriately identified and honestly dealt with
- Whether the information about different interventions is presented 'fairly' in a 'balanced' and unbiased way
- Whether the style and the tone of the leaflet were appropriate, and if not how they could be improved

You might want to ask the people who comment on your draft to apply a specific quality checklist. These can be especially useful if they have been designed specifically for the type of information package you are producing. However, not all checklists will be suitable for the type of information package you have developed and not all are designed to elicit suggestions about how to improve a package.

It is important to ask people who comment on your draft to explain their criticisms and suggestions as fully as possible. You need to know why they think something is incorrect or inappropriate, or why they think their suggested alteration represents an improvement. If they think that your information is inaccurate, ask them to provide research evidence or references so that you can follow up their concerns.

The number of times feedback on drafts should be sought will vary depending on the nature of the topic and the kinds of response that you get. We advise you

to seek feedback on at least two drafts because suggestions made on an initial draft are likely to require the addition of or changes to information, and it is important that all of the information provided is carefully checked.

Once you have a near-final draft, you might also try distributing it in a limited way and seeking feedback from the people who use it in a real life setting.

How should feedback be handled and used?

If you take the trouble to seek comments to help you improve your draft, it obviously makes sense to consider any feedback you get seriously. However, it is not always possible to incorporate all the changes that people suggest - not least because you may find that different people suggest incompatible changes! It is important to distinguish between factual inaccuracies, concerns that important information has been omitted (or unnecessary information included) and matters of taste in terms of the ways things are expressed. Try to be aware of any particular biases among your reviewers and consider their suggestions carefully in terms of whether they will improve the information package.

If you are seeking information from a number of people, it is probably advisable to consider all their comments together before you start making changes to the text. You might find it helpful to discuss the comments at a project team meeting to agree how you will respond to them.

If possible, you might try to explain to reviewers why you have not made all of their suggested changes. This could be done in the context of a standard thank you letter sent to all reviewers.

Post-distribution reviewing and updating of information materials

Knowledge about health and health care is not static, and even the best health information materials will not remain accurate and relevant forever. As time goes on, our understanding of the causes and mechanisms of diseases improves, new treatments are developed, more research is conducted to investigate their effects, judgements about the appropriateness of particular recommendations change, and there are shifts in health policy and clinical practice.

The information materials that are given to health services users need to be reviewed and either updated or withdrawn if they become out-dated. There are no hard and fast rules about how regularly information materials should be reviewed. Those that cover topic areas in which treatments are developing rapidly or in which research into treatment effects is ongoing will need to be reviewed more often than those which are less active in research and development terms.

If you are responsible for health information materials on particular topics, you may want to devise a strategy to ensure that you find about any important developments or new research evidence. Your strategy might include regular searches of relevant sources of research-based information. You might also try at periodic intervals (perhaps annually) to check with relevant subject experts that they still think the information is up-to-date, and to check with health care professionals and members of the intended audience that they still think the information package is useful. You might consider providing contact details on the information package and encouraging people to contact you if they think that any of the information provided is inaccurate or out of date.

Sometimes, new information or changes in policy and practice will make the information and advice in your materials less than ideal, but not likely to be harmful. If this is the case, you might decide to amend your package at the next reprinting or production run (and you might consider bringing forward the reprinting or reproduction date). At other times, however, new information or changes in policy and practice might make the information and advice in your materials seriously misleading or possibly harmful. If this is the case, the materials should be withdrawn (and if possible revised). You may need to contact the people/organizations who distribute it, and the organizations that maintain databases of information materials to ensure that it is removed from circulation as soon as possible.

If your information materials are clearly marked with production and revision dates or issue numbers, it will be easier for distributors to tell whether they are using the most current versions.

**Useful
References
and
Organizations**

Useful references and organizations

These are divided into the following sections:

- Articles and books about the quality of health information
- Checklists for assessing the quality of health-related information
- Guides to producing health information and/or involving people in health care
- Accounts of the production of information materials
- Sources of information to inform the content of your materials
- Organizations providing advice on information production and involving people in health care
- Sources of advice on provision of information to people with special communication needs
- Other useful sources of information for information producers in Scotland
- Scottish policy documents

Articles and books about the quality of health information

Coulter A, Entwistle V, Gilbert D. Informing patients: an assessment of the quality of patient information materials. London: King's Fund, 1998. [You can order a copy of this book via the website <http://www.kingsfund.org.uk>

Entwistle VA, Sheldon TA, Sowden AJ, Watt IS. Supporting consumer involvement in decision making: what constitutes quality in consumer health information? *International Journal for Quality in Health Care*, 1996; 8: 425-437.

European Commission. eEurope 2002: quality criteria for health-related websites. Available via the website: <http://www.jmir.org/2002/3/e15/index.htm>

Entwistle V. Patients' information environments: deserts, jungles and less hostile alternatives (Editorial). *Health Expectations*, 2003; 6: 93-96.

Garlick W. Patient information: what's the prognosis? Consumers' Association Policy Report. London: Consumers' Association, 2003.

Olszewski D, Jones L. Putting people in the picture: information for patients and the public about illness and treatment. Edinburgh: Scottish Association of Health Councils, 1998.

Checklists for assessing the quality of health information

Centre for Health Information Quality. Guidelines for reviewing health information. Available via the website: http://www.hfht.org/chiq/reviewers_guidelines.htm

Coulter A, Entwistle V, Gilbert D. Informing patients: an assessment of the quality of patient information materials. London: King's Fund, 1998. (The checklists given to academic specialists who were asked to review the information materials are provided in the appendix). [You can order a copy of this book via the website <http://www.kingsfund.org.uk>]

Charnock D. The DISCERN handbook: quality criteria for consumer health information on treatment choices. Oxford: Radcliffe Medical Press, 1998. Available via the website http://www.discern.org.uk/discern_instrument.htm

Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *Journal of Epidemiology and Community Health*, 1999; 53: 105-111.

Shepperd S, Charnock D, Cook A. A 5 star system for rating the quality of information based on DISCERN. *Health Information and Libraries Journal*, 2002; 19: 201-205.

Guides to producing health information and/or involving people in health care

CERES (1994). Spreading the word on research. On writing patient information leaflets. Available via the website: <http://www.ceres.org.uk/>

Department of Health. Good Practice in Consent Implementation Guide. Available via the website: <http://www.doh.gov.uk/consent/>

Department of Health. Toolkit for Producing Patient Information. Available on the NHS Identity website at www.doh.gov.uk/nhsidentity.

Duman M. Producing patient information: how to research, develop and produce effective information resources. London: King's Fund, 2003.

Parroy S, Thoms G, Williamson C. The practicalities of developing patient information. In: Lack JA, Rollin AM, Thoms G, White L, Williamson C. Raising the standard: information for patients. London, Royal College of Anaesthetists, 2003. pp15-23)

Scottish Executive Involving People Team. Building Strong Foundations. Involving people in the NHS: some practical guidance on approaches. Edinburgh: Scottish Executive, 2002.

Secker J, Pollard R. Writing leaflets for patients: guidelines for producing written information. Edinburgh: Health Education Board for Scotland, 1995.

Accounts of the production of information materials

Entwistle VA, Watt IS, Davis H, Dickson R, Pickard D, Rosser J. Developing information materials to present the findings of technology assessments to consumers: the experience of the NHS Centre for Reviews and Dissemination. *International Journal of Technology Assessment in Health Care*, 1998; 14: 47-70.

Glenton C, Polit C. Developing patient-centred information for back pain sufferers. *Health Expectations*, 2002; 5, 319-329.

Herxheimer A, McPherson A, Miller R, Shepperd S, Yaphe J, Ziebland S. Database of patients' experiences (DIPEX): a multi-media approach to sharing experiences and information. *Lancet*, 2000; 355: 1540-43

Moumjid N, Morelle M, Carrere MO, Bachelot T, Mignotte H, Bremond A. Elaborating patient information with patients themselves: lessons from a cancer treatment focus group. *Health Expectations*, 2003; 6: 128-139.

Rollin AM. The development of specialist booklets. In: Lack JA, Rollin AM, Thoms G, White L, Williamson C. *Raising the standard: information for patients*. London, Royal College of Anaesthetists, 2003. (pp24-29)

Sources of information to inform the content of your materials

Resources

Bandolier. Monthly news sheet and web site giving up-to-date information about clinical evidence. Available via the website <http://www.jr2.ox.ac.uk/Bandolier/>

Clinical Evidence. BMJ Publishing. Summarises the current state of knowledge and uncertainty about the prevention and treatment of clinical conditions, based on thorough searches and appraisal of the best available research evidence. It is updated every six months in print and monthly on line. Available via the website: <http://www.evidence.org>

Cochrane Database of Systematic Reviews

This includes the full texts of systematic reviews of the effects of health care 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 which have passed a minimum quality threshold and the Health Technology Assessment Database which contains information on health care technology assessments.

Available on CD-ROM and via the website: <http://www.cochrane.org/>

DIPEX

The Database of Individual Patient Experiences (DIPEX) is a particularly useful multimedia source of information about people's experiences of health conditions and treatments, although it currently only covers a limited range of topics. Available via the website: <http://www.dipex.org>

TRIP database

This database searches over 75 internet sites of high-quality medical information and gives direct, hyperlinked access to the largest collection of 'evidence-based' materials on the web as well as articles from premier on-line journals.

Available via the website <http://www.tripdatabase.com/>.

Organizations**National Coordinating Centre for Health Technology Assessment. (NCCHTA)**

This centre coordinates the Health Technology Programme under contract from the Department of Health's R & D Division. NCCHTA is a member of the International Network of Agencies for Health Technology Assessment (INAHTA) that promotes and facilitates information exchange and collaboration among HTA agencies. Summaries and full text versions of HTA monographs can be downloaded via the website:

<http://www.hta.nhsweb.nhs.uk/>

National Institute for Clinical Excellence (NICE)

Its role is to provide patients, health professionals and the public with robust and reliable guidance on current 'best practice'. The guidance covers both individual health technologies (including medicines, medical devices, diagnostic techniques and procedures) and the clinical management of specific conditions.

Contact details:

MidCity Place
71 High Holborn
London
WC1V 6NA

Telephone: 020 7067 5800

Fax: 020 7067 5801

Email: nice@nice.nhs.uk

Website: <http://www.nice.org.uk/>

NHS Centre for Reviews and Dissemination

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

Contact details:

University of York
York
YO10 5DD

Tel: 01904 433634

Fax: +01904 433661

Email: revdis@york.ac.uk

Website: <http://www.york.ac.uk/inst/crd/>

NHS Quality Improvement Scotland

Its role is to improve the quality of health care in Scotland by setting standards and monitoring performance, and by providing advice, guidance and support to NHSScotland on effective clinical practice and service improvements.

Contact details:

Elliott House
8-10 Hillside Crescent
Edinburgh
EH7 5EA

Website: <http://www.nhshealthquality.org/>

Scottish Intercollegiate Guidelines Network (SIGN)

Develops and publishes evidence-based clinical practice guidelines for use by the health service in Scotland.

Contact details:

Scottish Intercollegiate Guidelines Network
Royal College of Physicians
9 Queen Street
Edinburgh
EH12 1JQ

Tel: 0131 225 7324

Website: <http://www.sign.ac.uk/>

Organizations providing advice on information production and involving people in health care**Centre for Health Information Quality (CHIQ)**

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.

Highcroft
Romsey Road
Winchester

S022 5DH

Tel: 01962 872264

Email: admin@chiq.org

Website: <http://www.hfht.org/chiq/>

Consumer Health Information Consortium (CHIC)

CHIC is a support organisation which provides study days, encourages good practice and promotes the principle of free, open access to health information for all.

Contact details:

CHIC Treasurer

C/o Lambeth, Southwark and Lewisham Health Authority

1 Lower March

London SE1 7NT

Tel: 020 7928 9292

Web: <http://omni.ac.uk/CHIC>

Consumers for Ethics in Research (CERES)

CERES promotes the idea that consumers have a contribution to make to the design and conduct of medical research. The group also has a particular interest in the provision of good quality information to people who are invited to participate in health-related research.

Contact details:

Consumers for Ethics in Research

PO Box 1365

London

N16 0BW

Email: info@ceres.org.uk

Website: <http://www.ceres.org.uk/>

Patient Information Forum (PIF)

The members of PIF produce information for patients and carers, mainly within the NHS, but also in the independent and voluntary sectors.

Contact details:

Co-ordinator

28 Queensbury Street

London

N1 3AD

Tel: 020 7688 9208

Fax: 020 7704 9697

Website: <http://www.soi.city.ac.uk/~mjl/pif.htm>

Plain English Campaign

The Plain English Campaign encourages organizations to communicate clearly with the public. They run training courses on writing in plain English including a course on making medical jargon more simple. They 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.

PO Box 3, New Mills

High Peak

SK22 4QP

Tel: + 44 (0) 1663 744409

Fax: +44 (0) 1663 747038

Email: info@plainenglish.co.uk

Website: <http://www.plainenglishcampaign.com>

Sources of advice on involvement of and provision of information to people with special communication needs

AGE Concern Scotland

Provides information and publications to meet the needs of older people living in the community and to disseminate best practice for those working with older people.

Leonard Small House
113 Rose Street
Edinburgh
EH2 3DT
Tel: 0131 220 334

e-mail: enquiries@acscot.org.uk

Website: <http://www.ageconcernscotland.org.uk/>

Commission for Racial Equality (CRE) Scotland

Source of advice on identifying local minority groups within your area.

The Tun
12 Jackson's Entry
off Holyrood Road
Edinburgh
EH8 8PJ
Tel: 0131 524 2000

Email: scotland@cre.gov.uk

Website: <http://www.cre.gov.uk/scotland/index.html>

Disability Discrimination Act (1995), HMSO, London.

Available via the website: <http://www.disability.gov.uk>

MENCAP

Provides documents about making information more accessible to people with learning difficulties.

MENCAP
123 Golden Lane
London
EC1Y 0RT
Tel: 020 7454 0454

Email: information@mencap.org.uk

Website: <http://www.mencap.org.uk/>

National Information Forum

A voluntary organization committed to encouraging the provision of accessible information, by every means possible, for disabled people, asylum seekers, refugees and anyone else disadvantaged in gaining access to information.

Contact details:

Post Point 905
BT Burne House
Bell Street
London
NW1 5BZ
Tel: 020 7402 6681

Website: <http://www.thedrawingoffice.demon.co.uk/nif>

Royal National Institute for the Blind (RNIB) Scotland

The RNIB produces factsheets about various ways of making information accessible to visually impaired people.

Dunedin House

25 Ravelston Terrace

Edinburgh

EH4 3TP

Tel: 0131-311 8500

Fax: 0131-311 8529

Email: Cservices@rnib.org.uk

Website: <http://www.rnib.org.uk>

Royal National Institute for the Deaf (RNID)

Can book a sign language interpreter, lipspeaker or any other communication service through one of RNID's Communication Service Units which are situated throughout the UK. RNID also run a range of training courses for people to learn communication skills.

Contact details:

Floor 3

Crowngate Business Centre

Brook Street

Glasgow

G40 3AP

Tel: 0141 554 0053

Website: <http://www.rnid.org.uk/>

Scottish Accessible Information Forum (SAIF)

SAIF aims to make information more accessible to everyone who needs it. It supports the rights of disabled people and carers in having access to timely and accurate information about a wide range of services.

Royal Exchange House

100 Queen Street

Glasgow

G1 3DN

Tel: 0141 226 5261

Website: <http://www.saifscotland.org.uk/>

Other Useful Sources of Information for Information Producers in Scotland**Clinical Negligence and Other Risk Indemnity Scheme (CNORIS)**

CNORIS is a risk management scheme for the NHS in Scotland. It provides cost – effective claims management and financial risk pooling arrangements for all of Scotland's NHS Trusts and Health Boards and encourages a rigorous and logical approach to risk management in both the clinical and non-clinical sectors of the NHS in Scotland.

Available via the website: <http://www.cnoris.com/>

Confidentiality and Security Advisory Group for Scotland (CSAGS).

The Confidentiality and Security Advisory Group for Scotland (CSAGS) is responsible for providing advice on the 'confidentiality and security of personal health related information to the Scottish Executive, the Public and to Health Care Professionals.

Website: <http://www.show.scot.nhs.uk/csags/>

Focal Institute of Scottish Health Informatics (FISHI)

E-mail discussion list for all researchers, developers, implementers, trainers, and users of health informatics in Scotland available via the following website:

<http://www.jiscmail.ac.uk/lists/FISHI.html>

Information and Statistics Division

The Information and Statistics Division collects, validates, interprets and disseminates data regarding health service activity, manpower and finance. This data is received from Unified Boards, NHS Trusts and General Practices.

Contact details:

Trinity Park House

South Trinity Road

Edinburgh

EH5 3SQ

Tel: 0131 551 8899

Website: <http://www.show.scot.nhs.uk/isd/>

NHS Health Scotland

On 1st April 2003, the Health Education Board for Scotland (HEBS) and the Public Health Institute of Scotland (PHIS) merged to become NHS Health Scotland.

Contact details:

Woodburn House

Canaan Lane

Edinburgh

EH10 4SG

Tel: 0131 536 5500

NHS 24

Telephone health advice and information services that is being introduced across Scotland. The service is currently available in Grampian, Highland, Greater Glasgow and Ayrshire and Arran and will be available to the whole of Scotland by the end of 2004.

Tel: 0845 4 24 24 24

Website: <http://www.nhs24.com/>

Scottish Health on the Web

Scottish Health on the Web (SHOW) is provided by the National Health Service in Scotland and funded by the Scottish Executive Health Department. Its purpose is to provide a focal point for National Health Service in Scotland websites.

Website: www.show.scot.nhs.uk

Voluntary Health Scotland

Voluntary Health Scotland is an umbrella group which seeks to represent the interests of the voluntary health sector in Scotland and establish strategic partnerships with statutory sector.

Contact details:

11 Waterloo Place

Edinburgh

EH1 3BG

Tel: 0131 551 8351

Website: <http://www.vhscotland.org.uk/>

Scottish policy documents

The list below includes documents mentioned in the guide and other recent documents that make reference to information provision within NHS Scotland. Most are available via Scotland's Health on the Web at: <http://www.show.scot.nhs.uk/>

Fair for All. Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland. Edinburgh: Scottish Executive, 2002.

Our National Health: delivering change. Edinburgh: Scottish Executive, 2001.

Our National Health: a plan for action a plan for change. Edinburgh: Scottish Executive, 2000.

Partnership for care: Scotland's health white paper. Edinburgh: Scottish Executive, 2003.

Patient focus and public involvement. Edinburgh: Scottish Executive, 2001.

Protecting Patient Confidentiality. Confidentiality and Security Advisory Group for Scotland (CSAGS), 2002.