How to present the evidence for consumers: preparation of consumer publications

Handbook series on preparing clinical practice guidelines

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NHMRC
National Health and Medical Research Council

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PREFACE

Clinical practice guidelines are systematically developed statements to assist clinicians, consumers and policy makers to make appropriate health care decisions. Such guidelines present statements of 'best practice' based on a thorough evaluation of the evidence from published research studies on the outcomes of treatment or other health care procedures. The methods used for collecting and evaluating evidence and developing guidelines can be applied to a wide range of clinical interventions and disciplines, including the use of technology and pharmaceuticals, surgical procedures, screening procedures, lifestyle advice, and so on.

In 1995, recognising the need for a clear and widely accessible guide for groups wishing to develop clinical practice guidelines, the National Health and Medical Research Council (NHMRC) published a booklet to assist groups to develop and implement clinical practice guidelines. In 1999 a revised version of this booklet was published called *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1999), which includes an outline of the latest methods for evaluating evidence and developing and disseminating guidelines.

The emerging guideline processes are complex, however, and depend on the integration of a number of activities, from collection and processing of scientific literature to evaluation of the evidence, development of evidence-based recommendations or guidelines, and implementation and dissemination of the guidelines to relevant professionals and consumers. The NHMRC has therefore decided to supplement the information in the guideline development booklet (NHMRC 1999) with a series of handbooks with further information on each of the main stages involved. Experts in each area were contracted to draft the handbooks. An Assessment Panel was convened in June 1999 to oversee production of the series. Membership of the Assessment Panel and the writing group for this handbook are shown at Appendix A.

Each of the handbooks in the series focuses on a different aspect of the guideline development process (review of the literature, evaluation of evidence, dissemination and implementation, economic assessment and so on). This handbook focuses on how to prepare guideline information in a way that consumers can readily access and understand. It is considered particularly important that consumers should be able to access the information they need to help them understand all the issues relating to their health care.

The way in which the guidance provided in this handbook fits into the overall guideline development process recommended by the NHMRC is shown in the flowchart on page ix. Other handbooks that have been produced in this series so far are:

How to Review the Evidence: Systematic Identification and Review of the Scientific Literature

How to Use the Evidence: Assessment and Application of Scientific Evidence

How to Put the Evidence into Practice: Implementation and Dissemination Strategies

How to Compare the Costs and Benefits: Evaluation of the Economic Evidence

The series may be expanded in the future to include handbooks about other aspects of the guideline development process, as well as related issues such as reviewing and evaluating evidence for public health issues.

Flow chart showing the clinical practice guidelines development process
(The shaded box shows the stage described in this handbook)

Define topic/issue

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Assess need for guidelines, eg:
- Is issue related to clinical decision making?
- Are there suitable existing guidelines?

↓

Convene multidisciplinary committee
to develop guidelines

↓

Develop health care questions appropriate
for intended guidelines

↓

Identify (or commission) systematic reviews of the scientific
literature relating to these health care questions

↓

Assess evidence for
- strength
- size and effect
- relevance

→ Compare costs and benefits
of health care interventions

↓

Apply evidence to clinical/health care
situation to determine benefits/harms

Apply evidence to clinical/health care
situation to determine cost-effectiveness
and feasibility

↓

Develop and publish evidence-based
guidelines or update existing guidelines

Develop publication(s) to explain
guidelines to consumers

↓

Disseminate and implement guidelines

Develop publication(s) to explain
guidelines to other user groups,
eg general practitioners

↓

Maintain, evaluate and update guidelines

INTRODUCTION

Development of evidence-based guidelines

The process for clinical practice guideline development is described in the National Health and Medical Research Council (NHMRC) publication *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1999). This recommends that clinical practice and other related guidelines should be developed by a multidisciplinary guideline development committee, the initial task of which is to determine the need for and scope of the guidelines, define the purpose and target audience and identify the health outcomes that will improve as a result of their implementation.

The membership of the guideline development committee will depend on the nature of the particular guidelines being developed but will include clinicians, health professionals, consumers, health policy analysts, economists and regulatory agency representatives, industry representatives and bioethicists (see NHMRC 1999 for a full list and further discussion of the multidisciplinary committee).

Once the evidence has been assessed and guidelines developed for a particular issue, the next important task for the guideline development committee is to ensure that an implementation program is in place and that the guidelines are disseminated to all the target groups who need to have access to the information. This includes health professionals at various stages of the health care process and, most importantly, the general public who are the consumers of the services. Implementation methods are described in detail in another handbook in this series (*How to Put the Evidence into Practice: Implementation and Dissemination Strategies,* NHMRC 2000a).

This handbook focuses on the important issue of how to prepare information for consumers. It is a response to consumer requests for better information and has been based on a review of the relevant scientific literature about how to prepare and present evidence-based information for consumers of health services. Further details and evidence for many of the issues raised in this handbook can be found in the literature review, which is available on the Internet at the NHMRC website (www.nhmrc.health.gov.au/publicat/cp-home.htm).

The guidance provided is relevant to all kinds of health information in a variety of settings. It may relate to, for example, the decision to smoke or not (prevention), undergo a particular test or not (diagnosis) or accept a particular treatment (intervention) or not (prognosis). These types of health care questions

are discussed in more detail in another handbook in this series (*How to Review the Evidence: Systematic Identification and Review of the Scientific Literature*, NHMRC 2000b).

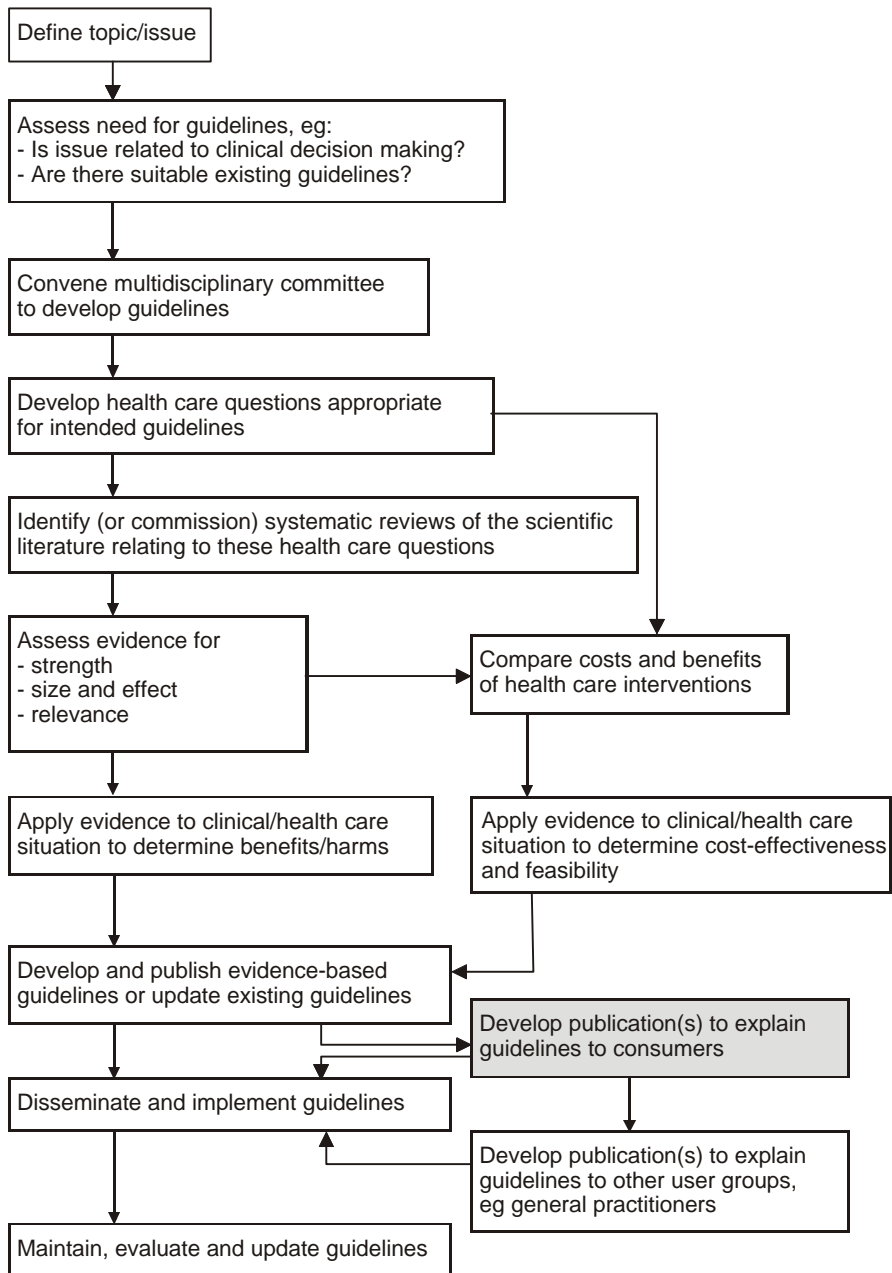This handbook is aimed at assisting guideline development committees and others to prepare and produce information for consumers of health services.

Consumers' need for information

Consumers should have a voice in all health care decisions — in what services are provided and in the clinical decisions that affect their lives.

Consumers need information in order to participate fully in decision making. Information is readily accessible through mass publication, mass media and the Internet, but to be useful, it also needs to be valid and understandable. Valid information, for at least some services and treatments, is now available through evidence-based medicine and initiatives such as the Cochrane Collaboration. The challenge for health care providers is to combine these resources to produce information that is accessible and useful for consumers in decision making.

Information to support clinical decision making is different from general patient education material. To support decision making, consumers need information on alternatives, benefits and risks, detailed descriptions of possible outcomes, tailoring of information to the individual's risk profile and ways of considering the individual's values as part of the deliberations. To provide such information is not easy.

We need to acknowledge that both the shift to shared decision making in health care and evidence-based medicine are new initiatives. However, evidence-based material on how to prepare and present information for consumers is limited so we have drawn on published material — evidence-based as far as possible and some consensus-based — while adding practical experience.

It is worth repeating the NHMRC's principles regarding the development of guidelines, whether the guidelines are intended for consumers or for health care providers (NHMRC 1999). Information for consumers should be as rigorously prepared, as evidence-based and as broad-ranging as information for health professionals. It is demeaning to consumers to consider there is information that professionals need that consumers do not.

The overall principles are that information should be:

- outcome focused;
- based on best available evidence;

- developed by multidisciplinary groups including consumers;
- flexible and adaptable to varying local conditions;
- evaluated for their validity and usefulness; and
- updated regularly.

There are many rationales for providing high quality information for consumers. There is the simple fact that it is the consumer's health, not the health professional's, at stake. There is courtesy. There is the educative role of a professional.

But there is also expectation that good communication improves health outcomes. According to the Toronto consensus statement of 1991 (Simpson et al 1991):

- communication problems in medical practice are both important and common;

- patient anxiety and dissatisfaction is related to uncertainty and lack of information, explanation and feedback from the doctor;

- doctors often misperceive the amount and type of information patients want;

- the quality of clinical communication is related to positive health outcomes;

- explaining and understanding patient concerns, even when they cannot be resolved, results in significant falls in anxiety;

- greater participation by the patient in the encounter improves satisfaction, compliance and outcome of treatment;

- the level of psychological distress in patients with serious illness is less when they perceive that they have received adequate information; and

- beneficial clinical communication is feasible routinely in clinical practice and can be achieved during normal clinical encounters, without unduly prolonging them, providing that the clinician has learned the relevant techniques (Simpson et al 1991).

Consumer publications are an aid to, but not a replacement for, good communication between consumers and health care professionals.

Please note that the term 'publication' is used throughout this booklet. This includes all the standard print-based media, but also covers computer-based information and electronic media such as video, audiotapes and television. It is not intended to be restrictive.

1   THE ROLES OF CONSUMERS

1.1   Involvement in health care

Preparing information for consumers demands that authors take into account the different types of consumers. Some are well educated, others less so. Some are well informed, others are not. Some are well versed on the vagaries of the health system, some are not.

While some consumers wish to make their own decisions (active), or to make them with their doctor (shared), others prefer to leave decisions to their doctor (passive). In three studies in two countries by Degner and Sloan (1992), Degner et al (1997) and Davison et al (1995), 34–59% of consumers preferred to leave decisions to their doctor, 23–44% wanted to make collaborative decisions and 12–22% wanted to make decisions regarding treatment on their own. All approaches are valid.

The practical implication of this is that if efforts are made to provide information, then it must be of a high enough standard that:

- those consumers who wish to leave the decision to their doctors can judge the wisdom of that decision;

- those who prefer a collaborative approach can do so from a sound knowledge base; and

- those who prefer to make their own decisions — perhaps three million Australians — can do so wisely and safely.

This means one publication will not suit all people. If you intend to reach all consumers with a particular medical condition or all consumers considering a particular clinical decision, then a range of information materials will be needed. The materials may range from a pamphlet with simplified instructions for people who prefer a passive role, to a sophisticated computerised decision-support package for those who wish to make their own clinical decisions.

1.2   Involvement in production of consumer publications

The NHMRC has recommended elsewhere that consumers should be involved in the preparation of clinical practice guidelines (NHMRC 1999). Indeed it is a

widely held view that consumers should be involved in the development of all health publications that could affect them.

Coulter et al (1999) arranged for 62 consumers to form focus groups and review 54 separate consumer information publications. They found the publications quite unsatisfactory. Yet most authors of the publications said they had involved consumers. A common failing was that, instead of being involved from the start, individual lay readers or consumer group representatives were asked to comment on the design and content of an existing draft.

More recently, clinical practice guidelines have been developed by multidisciplinary teams. Consumers have been full members of these teams, with considerable involvement. The consumers have shaped the guidelines from the start, and the resulting documents have shown the benefits of the consumers' input (M Ragg, personal communication).

Key points — role of consumers

1. Different consumers want different levels of involvement in their health care; some want to make their own decisions, some want to share responsibility with their doctor and some want to leave the decisions to their doctor.

2. Different levels of involvement by consumers means that different styles of publication may be required.

3. To ensure the right questions are answered at the right level, consumers must be involved at all stages in the production of consumer health publications, not just as reviewers at a late stage.

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2   PLANNING

Any publication should be planned thoroughly before a word is written. There are four essential questions which must be asked.

- Do consumers need or want information on this topic?
- How will we get the information to them?
- Can we afford to do it properly?
- How will we know if it has been worthwhile?

Entwistle et al (1998) suggested that the quality of a publication is determined by the degree to which it fulfils its stated purpose, and the consequences of its use. This has two implications — that the purpose of a publication should be clearly stated before it is prepared, and kept in mind throughout, and that its quality should be judged on its results. Plans for dissemination, implementation and review of any publication are an essential part of developing a publication, rather than an afterthought. This is discussed in more detail in another handbook in this series (*How to Put the Evidence into Practice: Implementation and Dissemination Strategies*, NHMRC 2000a).

Key points — planning

1. Before starting work on the publication four questions should be answered. Is there a need? Can we fulfil the need? Have we the money to do it? How can we assess what we have done?

2. The purpose of the document should be clearly stated.

3. Plans for dissemination, implementation and review of the publication should be included at an early stage of development.

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3   PROCESS

3.1   Overview

Developing a consumer publication is a lengthy process if carried out properly.
From planning to publication can take a year or more. The NHMRC
recommends a process that involves forming a working party with consumer
representatives. The first task is to decide whether or not there is a need and
whether existing publications can fulfil that need. If it is determined that there is
a need, the aim and target audience(s) must be clearly defined (taking into
account the needs of minority groups).

The working party will need to appoint a project officer, professional
communicator and graphic designer or producer, and determine the best means
(format, content, distribution strategies and implementation strategies) to reach
the target audiences and the forms of evaluation that can be used.

Once a list of consumers' questions that the publication should answer has been
developed and the available evidence reviewed/collated, a first draft can be
prepared. At this stage it is important to assess the reading level of the draft and
obtain consumer and professional reviews. Revisions of the draft may be
required before publication. The dissemination and implementation strategies
can then be carried out (if not already started) and the evaluation procedures
undertaken to form a basis for future updates.

Each stage of the process is described in more detail in the remainder of this
section. Of course, many of these stages overlap. For example, forming a group
at the start can be part of the implementation strategy if the group is drawn
from a wide range of professional and consumer groups, and the members
promote the publication within their spheres of influence.

3.2   Form a working party and involve consumers

A multidisciplinary group should be formed to carry out the process, and a
chair appointed. Ideally, working parties should be fairly small. The group
should contain at least one representative from each relevant health profession
and, if necessary, from each discipline within that profession. This should be
balanced with a number of consumers. There should be a mix of those with
direct experience of the health issue being considered, and those with advocacy
skills and links to the consumer movement. A check should be made to ensure
that all key stakeholders are represented, as this can influence the success of
dissemination and implementation of the material.

Consumers should be genuine lay representatives. They should have no association with any hospital, health institution or health professional. It is not satisfactory, as is sometimes the case, to consider the hospital physiotherapist or a doctor's partner as a consumer. The Consumers' Health Forum defines a consumer representative as 'someone nominated by and accountable to an organisation of consumers'. It is helpful if at least some of the consumers involved have personal experience of the problem being discussed.

As long as the tasks laid out are achieved, the working group may choose to meet face-to-face, by teleconference, or communicate by email, etc.

3.3   Assess the need

The working party should decide on whether or not a consumer publication is required. It may be that a need is obvious — all concerned know that consumers are asking for information on the subject. If it is not clear-cut, then a focus group of consumers with experience of the relevant condition or process may be formed to discuss whether or not there is a need for information. Alternatively, a more formal evaluation could be carried out by surveying a representative sample of affected consumers and asking them whether they are satisfied with existing resources. This may involve giving them some or all of the existing resources and asking them to evaluate them using a framework such as that suggested by the DISCERN group (Charnock 1998) (see Section 4.2).

At this stage it is also important to consider the needs of groups other than able-sighted, literate, English-speaking people. Is there a need for such information in languages other than English? Is there a need for a video, which could reach people with poor literacy skills? Is there a need for the information to be produced in Braille? Is there a need for targeted information for older people? While these considerations are particularly important for certain conditions — for example, information on thalassaemia should probably be produced in Greek as well as in English, and information on cataracts in large print or on video — minority groups should be considered when all publications are being planned. If such a need exists, it must be addressed. To produce a publication in a language or format that cannot reach all the target audience may be a waste of resources. However, it is also a waste to produce resources in multiple languages or formats if no need exists. Needs must be assessed and addressed accordingly.

Overall, if a need for consumer documentation is demonstrated, the working party should check if suitable publications are already available that can be used, or licensed and reissued by another organisation. For example, the State and Territory anticancer councils all publish a range of documents. Many of these are identical in content but with different covers. This means that the

development costs are reduced and, for the organisation that did the initial work, may be defrayed. If other publications can fulfil the needs that have been identified, there is no need to proceed. If there are no suitable publications, then the working party should continue.

3.4   Determine the aim and target audience

Exactly what is the publication trying to achieve? Is it trying to ensure that clinical practice is in line with available research? Is it informing consumers about the range of options available? Is it trying to improve consumers' satisfaction with an institution?

Whatever the aims, they will influence many decisions about the publication. The aim of the publication should therefore be stated at the front of the document and evaluated after publication — did the material achieve its aim?

There are many potential target audiences. A publication aiming to encourage all people over the age of 40 to have their blood sugar level checked has a national target audience of almost half the population of Australia. A publication aimed at informing people with psoriatic arthritis about treatment options has a much smaller audience, comprising people already diagnosed with the condition.

Most publications will also have a secondary target audience. The secondary audience for the diabetes information mentioned above would be the doctors who would do the testing. A secondary target audience for the psoriatic arthritis document may be the small group of people who determine which drugs should or should not be listed on the Pharmaceutical Benefits Scheme and subsidised.

If it is difficult to define the target audience, perhaps the aim of the publication is still not clear and should be considered further.

3.5   Appoint a project officer, communications professional and designer

A project officer will be needed for various functions, such as to organise meetings, prepare and keep track of correspondence, make payments, coordinate the review of evidence, liaise with the head of the working party and its members, and carry out other general administrative tasks.

In general, health professionals have not been trained in communication, and have little practical experience of mass communication. They should not be relied upon to use skills they do not necessarily possess. Therefore, at an early

stage, a professional communicator should be employed. In addition to their main skills of writing, editing, video and/or audio production, the professional may offer skills in planning, reaching target audiences, marrying format with content and other useful areas.

Similarly, a writer or editor does not usually have the skills required to either design printed documents, or produce broadcast material. Nor do most health professionals. Bringing a professional in at this stage will help shape the rest of the process to achieve the best result.

3.6   Determine format and content

With the assistance of a communications professional and designer, major decisions regarding format, content, distribution strategies and implementation can be made.

These decisions should be made simultaneously. Form and content — as in music, art and literature — are inseparable. It is not possible to be comprehensive in an advertisement placed in community newspapers, and it is wasteful to decide that a catchy slogan says all you want to say, then produce booklets for distribution to all households.

Consumers should be involved directly and explicitly in developing a list of questions the publication should answer. It is important to decide whether or not the target audience can be reached with one publication. For example, if you want to reach all Australian women at risk of cervical cancer, you may decide you need at least two publications pitched at different reading ages, with different levels of complexity.

As discussed in Section 1.1, the level of involvement that consumers want varies between people and over time. People who prefer an active or collaborative role need more detailed information, whereas those who prefer a more passive role need less detail. As well as the list of consumer questions, the working party should also assess the range of decision-making preferences that consumers have with respect to the particular issue under consideration. These preferences can then guide the level of information provided in the publication(s) produced.

Content is discussed further in Section 4 and format in Section 6. Section 7 discusses the presentation of material within those two parameters.

3.7 Determine distribution, implementation and evaluation strategies

Distribution and implementation strategies are discussed in another handbook in this series (*How to Put the Evidence into Practice: Implementation and Dissemination Strategies,* NHMRC 2000a).

The evaluation should ask two questions.

- Did the publication reach its target audience?
- Did it achieve its aim?

The forms of evaluation that will be used should be documented and budgeted for at an early stage because evaluation is an essential part of the process.

3.8 Review available evidence

Consumer publications should be based on the same high standards as publications prepared for health professionals. Available evidence should be reviewed before drafting starts, so as to ensure the validity of the information.

Systematic reviews and meta-analyses should be used wherever possible. These can be obtained from the Cochrane Database of Systematic Reviews[1] or through MEDLINE or other similar computerised databases. Further details are given in another handbook in this series (*How to Review the Evidence: Systematic Identification and Review of the Scientific Literature,* NHMRC 2000b).

For clinical practice and other evidence-based guidelines, the evidence obtained from a systematic literature review will have been carefully reviewed by the multidisciplinary committee and recommendations made. Depending on the questions the consumers want answered, these may form the basis of the consumer guide.

3.9 Prepare first draft

A first draft should cover all areas required, as indicated by the consumer-developed list of questions and available evidence. It should not be merely a simplified version of a clinical practice guideline.

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[1] www.som.flinders.edu.au/fusa/cochrane

The first draft should cover, explicitly, areas of uncertainty or controversy. In some cases, there will be no evidence at all, but this should not rule out a discussion of the subject.

It is important that the material is of a level that is suitable for the intended target audience. Reading levels give one guide to the accessibility of written materials, and are quick and easy to perform. They will be discussed further in Section 7, and details are given in Appendix C.

3.10 Obtain health professional and consumer reviews

The first draft should be sent to a broad range of health professionals to be assessed for accuracy and thoroughness from their perspective. Comments and suggestions should be weighed up by a small group involving the writer/editor, a consumer and a health professional, preferably the head of the working party.

Once the draft is accepted as accurate, it should be sent to a broad range of consumers to be assessed for accuracy, thoroughness, accessibility and comprehensibility from their perspective. Comments and suggestions should be weighed up by the same small group.

The draft should be revised in accordance with comments and, if only minor changes are made, the working party should look at it again before publication. If substantial changes are made to the draft, then it needs to continue going to professional and consumer review until all are satisfied.

3.11 Publish

Publishing is an unpredictable process. It requires either the project officer or the communications professional to be responsible for liaison with designers, layout people, software designers, production staff, printers and so on, and a number of others from the group to be responsible for checking the material at every step of the way. Publishing requires great care and attention to detail.

3.12 Disseminate, implement, evaluate and update

The process does not end with publication, as this would be wasted without effective dissemination and implementation strategies. These should have been carefully developed by the working party early in the process and should now be carried out. Further information on implementation and dissemination is

given in another handbook in this series (*How to Put the Evidence into Practice: Implementation and Dissemination Strategies*, NHMRC 2000a).

The evaluation strategy developed by the working party should also be carried out and the result of the evaluation published.

Using the information from the evaluation and other new evidence that becomes available, consumer publications should be updated regularly. For some issues, every two years is sufficient. For others, more regular updates are required.

The due date for update, the people responsible for updating the publication and their budget for doing so should be determined in the planning stage. The date of publication should appear clearly and prominently on the published document, along with the due date of review. The publication should be considered invalid once past its due date for review.

Key points — process

1. Form a working party including consumer representatives.

2. Assess the need and search for existing publications that can fulfil that need.

3. Define the aim and target audience(s).

4. Appoint a project officer, professional communicator and graphic designer and establish a budget.

5. Determine the best means (format, content, distribution strategies and implementation strategies) to reach the target audiences and the forms of evaluation that can be used.

6. Develop a list of consumers' questions that the publication should answer.

7. Review/collate the available evidence and prepare a first draft.

8. Assess the reading level and obtain consumer and professional reviews of the draft.

9. Revise draft to ensure all aims have been met and consumer questions answered.

10. Disseminate, implement and evaluate the success of the publication.

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4   CONTENT

The content should be determined by two factors:

- what consumers want to know; and
- what health professionals do and don't know.

Consumers should drive the process, with professionals responding to their needs and desires.

4.1   Developing the content

4.1.1   What consumers want to know

A focus group of consumers who have had direct experience of the topic to be discussed should be formed. This focus group should be asked to develop a list of questions they would want answered. This list becomes the starting point for the publication.

Coulter et al (1998, 1999), working for the King's Fund in the United Kingdom, interviewed 62 consumers and distilled their questions into the following list.

- What is causing the problem?

- Am I alone? How does my experience compare with that of other consumers?

- Is there anything I can do myself to ameliorate the problem or prevent recurrence?

- What is the purpose of the tests and investigations?

- What are the different treatment options?

- What are the benefits of the treatment/s?

- What are the risks of the treatment/s?

- How likely are the benefits and risks?

- Is it essential to have treatment for this problem?

- Will the treatment/s relieve the symptoms?

- How long will it take to recover?

- What are the possible short-term and long-term side effects?

- What effect will the treatment/s have on my feelings and emotions?

- What effect will the treatment/s have on my sex life?

- How will it affect my risk of disease in the future?

- How can I prepare myself for the treatment?

- What procedures will be followed if I go to hospital?

- When can I go home?

- What do my carers need to know?

- What can I do to speed recovery?

- What are the options for rehabilitation?

- How can I prevent recurrence or future illness?

- Where can I get more information about the problem or treatments?

This list is a useful starting point, but it should be considered as no more than that. Obvious questions such as 'What usually happens in this disease without treatment?' and 'What is my prognosis?' do not appear on it. Also, this list is concerned mainly with treatment, and does not cover questions about diagnostic tests such as 'How accurate is this test?' and 'What will happen if the test is abnormal?' Nor does it cover preventive strategies.

However, there is no substitute for developing a topic-specific list of questions to be covered — a list developed by local consumers involved in the issue.

The focus group could also be asked their opinions about the format in which the information should be presented, and their recommendations regarding distribution.

Of course, not all information is of equal value to consumers, and in some publications, there would not be enough space to consider all those questions. Degner et al (1997) asked three groups of cancer patients (breast cancer, benign breast disease and prostate cancer) to rank their information needs. These are shown in Table 4.1.

If a publication is to be brief, such as a leaflet, consideration should be given to these priorities. A leaflet should also contain a note on where to get further information.

Table 4.1   Information priorities of consumers

High priority	Medium priority	Low priority
Chances of cure	Self-care at home	Effect on sexuality
Spread of disease	Impact on family	
Treatment options	Social activities	
Family risk		

Source: Degner et al (1997)

Consumer checklist for discussions with their doctor

As well as a thorough understanding of the issues involved in their health care choices and the evidence underpinning different options, consumers often find it helpful to prepare a written checklist of items to discuss with their doctor or health care professional at their appointment. Using the questions that have been considered most important for preparation of the consumer publication on a particular issue, it would be helpful to include in the publication a checklist of items that consumers can use as a starting point for compiling their own list.

4.1.2   What consumers already know

In the context of consumer publications, information providers should assume that consumers know nothing of the condition being discussed, or the treatment options, or even basic anatomy. Any publication should start from scratch.

In some cases, it should start from behind scratch. There are many areas in which mythology is common, and myths need to be dispelled. For example, a publication on palliative care would always need to dispel the myths about morphine — that it is addictive, that it speeds death, and so on. A publication on cancer will need to describe survival rates to dispel the idea that cancer is usually fatal.

Common myths and misconceptions may be identified from the focus group discussions.

4.1.3   Getting the message across

Be comprehensive

According to Coulter et al (1998), many consumer publications are flawed because of their decision to include only treatments or management strategies for which there is evidence. Consumers find this confusing because they know of the existence of treatments not included in publications (presumably because of a lack of evidence about effectiveness). Coulter et al (1998) argue it is better

to include all common practices or outcomes, and discuss them, even in the absence of evidence.

This will occur naturally if the authors work from the basis of consumer questions, rather than relying on evidence alone as the source of information.

Useful information about a condition that should be included in consumer information, but which consumers have indicated is often omitted, includes:

- causes
- consequences
- natural history
- prevalence
- recovery time
- range of outcomes, with probabilities (Coulter et al 1998)

Consumer documents should also consider costs of treatment, availability of treatment and access to treatment. It may not be possible for such publications to be detailed on these questions, particularly where a national resource is being produced and there is considerable regional variability, but the issues should be considered and addressed if possible. Links to other groups or resources that can provide the relevant information may be useful too.

Be accurate

Many consumer publications contain inaccuracies and misleading statements (Coulter et al 1998). The most common fault is to give an overoptimistic view of treatments, emphasising benefits and playing down risks and possible side effects. It is inaccurate to give an unbalanced view of benefit and risks (further information is given in Section 5.1).

The other main flaw is that publications may be written without reference to evidence. Evidence should come from systematic reviews or meta-analyses, randomised controlled trials or observational studies (such as cohort studies, case-control studies and case reports), all of which may show more or less statistically significant or clinically important effects. Another handbook in this series gives information on how to assess and use evidence (*How to Use the Evidence: Assessment and Application of Scientific Evidence*, NHMRC 2000c) and describes how the different 'dimensions' of evidence can be assessed as shown in Table 5.1.

For clinical practice guidelines, the multidisciplinary committee preparing the guidelines should have prepared checklists for the dimensions of evidence for each recommendation they include in the guidelines (see Section 5). These can then be considered on the basis of what consumers want to know. It is important that the committee preparing the consumer guide is very familiar

with the interpretation of evidence and their implications for clinical practice as they will form the basis of both clinical and consumer decision making.

Consumers need to clearly understand and weigh up the benefits and risks of a treatment or course of action that their doctor suggests. To do this, they need access to the evidence in an accurate and easily understandable form. A further discussion on how to explain risk in simple terms is given in Section 5.2.

Include sources of further information or consider multiple publications

No single publication can answer everyone's needs. Some people will find a simple publication sufficient, while some will always want more information. Degner et al (1997) found most people want to either share decision making, or leave decision making to their health care provider. For them, standard health education materials may be enough. In fact, those who want an entirely passive role may require only a very brief and simple publication.

However, a substantial minority of people (10–20%) want enough information to make clinical decisions without their health care provider. For this group, a useful publication will need to be quite detailed, including information on treatment or diagnostic options, risks and benefits, their own risk level and ways to incorporate their values and cultural preferences into their deliberations.

It may therefore be better to produce two or more versions of a publication ranging from simple and educative through to sophisticated decision-support aids in order to meet people's varying needs.

The costs of production of good quality, detailed consumer information may be high. Production of a short, simple version, with a full, more expensive publication available on a 'for loan' basis, could be one way to meet differing consumer needs.

Another strategy is to keep the publication brief but list sources of further information, which might include:

- relevant organisations, including support groups;
- consumer literature;
- consumer help lines;
- books; and
- professional literature, especially meta-analyses and recent overviews.

Consumer websites should be linked to all other sites that have been assessed and found useful, including the professional literature. Further information on finding evidence from computerised databases and the Internet can be found in Irwig et al (1999).

Relate the experience of others

Personal experience can be useful in two ways. One way is to make the consumer feel they are not alone. It is reassuring to read personal anecdotes and see photographs of people with similar problems.

The use of personal anecdotes — for example, in a video showing two people explaining their different choices in a similar situation — can also help with the decision-making process when the options are unfamiliar.

4.1.4   Other information

Be explicit about authorship and sponsorship

Readers have a right to know who has prepared a publication, as that will influence the weight they put on the views expressed within it. A multi-author publication may well include a broader range of views than one by a single author. A publication written by a health professional may have a different perspective than one from a consumer. An NHMRC booklet may differ from one by a pharmaceutical company.

Similarly, any level of sponsorship should be acknowledged.

Include a glossary

A glossary is a useful addition to a consumer publication, especially if used to give plain English definitions of medical terminology and jargon. However, it should not be used as an excuse to continue to use jargon throughout the body of the document. A glossary does not reduce the need for plain English.

Include the publication date and the date planned for review

The publication date is vital, as is the date at which a document should no longer be considered valid because it is due for review. Both should be stated clearly and conspicuously.

4.2   Checking the content

DISCERN, a group funded by the British Library and the National Health Service Research and Development Programme, has developed a checklist by which readers can assess the quality of consumer information regarding treatment options (Charnock 1998). Turning that approach around, information providers should use the checklist of questions to see if their publication meets the requirements of consumers.

- Are the aims clear?

- Does the publication achieve its aims?

- Is it relevant?

- Is it clear what sources of information were used to compile the publication?

- Is it clear who wrote and financed the publication?

- Is it clear when the information used in the publication was produced?

- Is it balanced and unbiased?

- Does it provide details of additional sources of support and information?

- Does it refer to areas of uncertainty?

- Does it describe how each treatment works?

- Does it describe the benefits of each treatment?

- Does it describe the risks of each treatment?

- Does it describe the costs — financial, temporal and social — of each treatment?

- Does it describe what would happen if no treatment is used?

- Does it describe how the treatment choices affect overall quality of life?

- Is it clear that there may be more than one possible treatment choice?

- Does it provide support for shared or independent decision making?

A similar checklist has also been produced by the Health Consumers' Council (*Best Practice Guidelines for Developing Patient Information*, 1996).

Key points — content

1. The content should be determined by what consumers want to know and what health professionals do and don't know.

2. The publication should start from scratch, with no previous knowledge assumed for consumers.

3. Options for which evidence is available should be described as well as those for which it is lacking.

4. Evidence for benefits and risks should be presented in an accurate and easily understandable form.

5. References to other sources of information should be included.

6. The content should be assessed against a quality checklist to ensure that the needs of consumers have been met.

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5   EXPLAINING THE EVIDENCE

5.1   Dimensions of evidence

As discussed in Section 4 the evidence for health interventions and procedures has a number of dimensions, which form the basis of clinical decision making.

In simple terms these include information on the type of trials or studies on which the evidence is based (*level of evidence*); how well the studies were done to eliminate bias (*quality of evidence*); the degree of confidence that the effect did not happen by chance (*statistical precision*); the size (or magnitude) of the effect seen and the inclusion of clinically important effects (*size of effect*); and the usefulness and appropriateness of the effect in practice (*relevance of evidence*). Further details of these dimensions are shown in Table 5.1. The first three dimensions (level, quality and statistical precision) collectively are a measure of the *strength of the evidence*.

Conveying these dimensions to consumers in simple terms will be challenging. The handbook on *How to Use the Evidence: Assessment and Application of Scientific Evidence* (NHMRC 2000c) gives a step-by-step guide on how to compile an evidence checklist that includes an assessment of each dimension. Examples of how this can be used to frame clinical guidelines are shown in Box 5.1.

Based on the list of questions that consumers want answered (see Section 4.1), the committee preparing consumer information needs to carefully weigh up the evidence checklists and decide on appropriate ways to answer consumers' questions.

5.2   Explaining risk

Central to discussing evidence with consumers is the communication of risk. This is extremely important because information about risks and benefits is vital for decision making but it is often difficult to understand and great care is needed in the presentation of this information.

The study of risk and perception of risk has developed its own literature, which was reviewed briefly as part of the literature search (see Introduction). Evidence from the literature confirms the difficulties of communicating risk, and indicates that the way risk is expressed determines how it is perceived.

Risk can be communicated by health professionals in two ways when they are discussing risk and changes in risk caused by treatments — absolute risk and relative risk.

Table 5.1   Evidence dimensions

Type of evidence ('dimension')	Definition
Level[a]	This describes the study design used (systematic review, randomised controlled trial, cohort study, etc). This is an indicator of how well bias was eliminated from the study and therefore of how likely it is that the results represent a true effect. Levels of evidence are categorised using the four-point scale described in the NHMRC guideline for preparing clinical practice guidelines (NHMRC 1999).
Quality[a]	This describes the methods used by investigators to minimise bias within a study, that is, how well the study has actually been done. Quality can be assessed using a standardised qualitative assessment scale.
Statistical precision[a]	This measures the precision of the result of the study, which is related to the *P*-value of the effect (as indicated by the confidence interval). It reflects the degree of certainty that the trial has measured a true effect.[b]
Size of effect	This measures the distance of the study estimate from the 'null' (control) value and the inclusion of clinically important effects in the confidence interval.
Relevance	This conveys the usefulness of the study results in clinical practice, particularly relating to the appropriateness of the outcome measures used. Relevance can be assessed using a standardised qualitative assessment scale.

[a] These three items collectively measure the *strength* of the evidence
[b] The *P*-value is the probability (obtained from a stastistical test) that the null hypothesis (that there is no treatment effect) is incorrectly rejected (ie the probability of claiming that there is a treatment effect when in fact there is no real effect)

Absolute risk describes the proportion of patients with an outcome. The *risk difference* is the difference in absolute risk between treated and untreated groups. If the treatment reduces the risk, the risk difference is called the *absolute risk reduction.*

Relative risk describes the risk of an outcome after treatment as a proportion of the original risk (that is, the risk in treated people divided by the risk in untreated people). If the relative risk is less than 1 (100%), this indicates that the treatment reduces risk and the *relative risk reduction* is usually quoted (1 − relative risk).

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Box 5.1   Use of evidence — examples

Note: The following examples are hypothetical and do not represent actual recommendations. Information was not available to fully construct the evidence checklist (including quality score, relative risk, *P*-value and so on), but the general approach is shown.

Example 1 — recommendation to avoid nonsteroidal anti-inflammatory drugs (NSAIDs) in subjects with a history of peptic ulceration

Evidence checklist

Level	Case-control studies (level III)
Quality	Good
Statistical precision	Small *P*-values
Size of effect	Large adverse effect of treatment
Relevance	Highly relevant outcome (hospitalisation with major gastrointestinal bleeding).

Conclusion

Although the evidence was obtained from observational studies, the other dimensions rated well and the recommendation can be supported.

Example 2 — Recommendation for the routine use of anticholinesterase drugs in the treatment of patients with Alzheimer's disease

Evidence checklist

Level	Randomised controlled trials (level II)
Quality	Good
Statistical precision	Small *P*-values
Size of the effect	Small positive effect of treatment
Relevance	Low (the duration of follow-up was too short in relation to the natural history of the disease and the outcomes measured were of doubtful relevance to patients and their carers).

Conclusion

Although the evidence was obtained from high quality randomised controlled trials, the other dimensions rated poorly and the recommendation cannot be supported.

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There is evidence that people are more likely to choose treatments when their benefits are expressed in terms of relative risk, not absolute risk (Naylor et al 1992; Forrow et al 1992; Malenka et al 1993; Hux and Naylor 1995; Fahey et al 1995; Wolf 1998). To put it simply, the numbers are larger and more impressive.

Perception of risk and benefit are further complicated by the way that benefits are often expressed in terms of relative risk, while complications are expressed in terms of absolute risk. For example, a document may say that tamoxifen

taken as chemoprevention may reduce the (relative) risk of breast cancer by 45%, while there is an (absolute) risk of thromboembolism of 2%.

Risk should be expressed in absolute terms, wherever possible. It is probably easiest to understand if the risks in the untreated and treated groups are explicitly stated. For example, in relation to hormone replacement therapy (HRT), the effect on the risk of heart disease could be expressed as:

> 'Without hormone replacement, 46 out of 100 women may have heart disease in their lifetime. With hormones, 7 to 12 fewer women (34–39 out of 100) may get heart disease.' (O'Connor et al 1996).

If absolute risk data are not available, then both risks and benefits should be expressed in relative terms.

5.2.1   Case studies

Appendix D describes two case study examples of consumer publications which have been trialled and evaluated. One was prepared to help women make a decision about whether or not to use HRT. The other was prepared to help men decide what treatment to have for prostate cancer. In each case, the risks and benefits associated with alternative strategies are presented.

Box 5.2 shows an example of how these terms are used.

Key points — explaining the evidence

1. The evidence for health interventions and procedures includes information on the types of trials or studies that have been done (level), how well they were done (quality), the statistical significance and size of the effect seen and whether it improves clinical outcomes (strength and magnitude), and is relevant for consumers (relevance).

2. An evidence checklist, including all these dimensions, should be assessed and the evidence appropriately presented to form the basis for consumer decision making.

3. Information about risks and benefits is vital for decision making.

4. The way risk is expressed (ie absolute or relative risk) determines how it is perceived.

5. Risk should usually be expressed as absolute risk (ie the proportion of patients with an outcome), rather than as relative risk (the risk in treated people relative to the risk in untreated people). It is best if the absolute risks in the untreated and treated groups are explicitly stated.

Box 5.2   Describing risk in absolute and relative terms

Result of clinical trial (evidence)

Without treatment 10% of patients with a particular cancer died within five years.
With treatment 7% of patients died within five years.

Absolute risk

The absolute risk of dying within five years is 7% with treatment and 10% without treatment.

The risk difference, or *absolute risk reduction*, is 3%.

Relative risk

The relative risk of dying within five years after treatment is 7% divided by 10%, or 70%.

The *relative risk reduction* after treatment is 30%.

Communicating the risk

Absolute risk reduction:
'This treatment will reduce your risk of dying within five years from 10% to 7%,

Relative risk reduction:
'This treatment will reduce your risk of dying within five years by 30% compared with people who are not treated.'

Conclusion

The two approaches to communicating the risk describe the same treatment and the same person — they are merely expressed differently.

When the underlying risk is low, relative risk will appear much more impressive than absolute risk reduction.

6   FORMAT

Print is the traditional medium for publishing information for consumers, but there are a number of other formats available — video, audiotape, telephone-based, computer-based and on the Internet. These will be considered below.

6.1   Print

Print has the advantage of seeming to be available to everybody. However, not all Australians can read adequately. The Australian Bureau of Statistics has classified Australians' reading skills as shown in Table 6.1:

Table 6.1   Reading skill levels of Australians, 1996

Level of reading skill	Australian population %
Very poor skills, likely to have considerable difficulties dealing with printed materials in everyday life	19.7
Some difficulty with printed materials in everyday life	27.5
Able to cope with a varied range of materials found in daily life and at work	35.3
Good literacy skills and able to use higher order skills associated with matching and integrating information and performing arithmetic operations	15.5
Very good literacy skills, able to make high-level inferences, use complex displays of information, process information and perform multiple operations sequentially	2.0

Source: Australian Bureau of Statistics (ABS 1997)

This means that only half of all consumers would read the first section of this booklet with reasonable ease. The other half would have difficulties, and one in five could not read it at all.

While print is the most common way of providing information to consumers, it will not reach all consumers.

6.2   Video

Most Australians are familiar with television, and 80% of households have a video recorder (Bureau of Transport and Communication Economics 1994). So consumer information based on video has quite good reach, and avoids problems with literacy.

Videos can be informative and engaging. They can show interviews with people who can describe their experiences of various treatments, screening tools and decisions.

However, videos are expensive to produce and distribute, and difficult to update. They are probably best reserved for the times when there is a fairly small target audience and a reasonable budget.

6.3   Audiotapes

Audiotapes are good for visually impaired people or those with poor literacy skills. They are reasonably cheap to produce, mass produce and distribute.

However, some people find it difficult to remember material they have heard, without seeing it as well, either on a page or on a video. Audiotapes may need to be supported by print material, rather than be used on their own.

6.4   Telephone-based information services

Another way to present information is to have recorded material on a telephone help line. Callers can select various options, in the manner of many modern corporate switchboards. At any time, there would need to be the option to go to an information officer.

This approach combines the traditional method of telephone counselling with the capabilities of telecommunications technologies. It would need to be supported by a range of materials, in case callers want further information.

6.5   The Internet and computer-based packages

The Internet is a relatively cheap form of publication and it is easy to update. It is popular and has a number of other benefits.

Importantly, information can be layered so that summaries can be provided at the front, and links made to information of greater depth. This allows

consumers of varying literacy levels to obtain the amount of information they want. The material can also be saved or printed for later reading, although publishers must make sure this is not a laborious task.

Information can also be linked to other websites or to journal articles of relevance.

However, the Internet is not yet widely available. It will take time before the Internet penetrates Australian households to the same extent as televisions, video recorders, audio cassette players and books, if it ever does. As of August 1998, 18% of homes had Internet access and 32% of adults had used the Internet in the previous 12 months. Those figures do not reveal how many people use the Internet well, but they do reveal that two in three consumers have not used it recently, and that four in five would have to leave home to access it.

Internet publishing appears to be a useful tool for reaching those people with access, but it should not be used as the sole means of publication.

Computer-based packages, such as CD-ROM presentations, can be interactive, making them highly suitable for decision-support packages. Consumers can supply information from which their individual risk of disease can be calculated by the package, and then used to estimate the magnitude of benefits and risk from various treatment or diagnostic options.

Computer packages can also take advantage of hypertext links to provide detailed information for those who want it, while 'hiding' detailed information from those who do not. This is a useful way of reducing exposure to threatening information for people who may not be ready for it. For example, someone who has recently been diagnosed with a life-threatening condition and who copes by avoiding information may not want to be exposed to objective information such as five-year survival rates. However, another person at a different time in the course of their illness and/or with different coping strategies may want this information, which could be accessed through a hypertext link.

6.6   One publication for all?

Some consumers have university degrees; others cannot read. Some love computers; others are afraid of them. Some love videos; others do not own a video recorder.

It will be impossible to produce any single publication that satisfies the needs of all potential audiences. However, keeping in mind the varied abilities, desires

and knowledge base among consumers, it is possible to produce a range of materials that satisfy most needs of most consumers.

Key points — format

1. Print is the most common format but other formats (video, audiotape, etc) should also be considered.

2. About 70–75% of people experience some difficulty reading and/or interpreting written information and may benefit from other formats.

3. A range of material may be required to satisfy the needs of all consumers.

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7   PRESENTATION

The main features of presentation that are worth considering in print publications (which form the majority of consumer publications developed) are language and design. These will be discussed below.

7.1   Language

Publications should be prepared so that they are appropriate for the literacy skills of the target audience. This means that many consumer documents should be prepared in such a way that they are accessible to people with poor literacy skills.

7.1.1   Simple language

Using simple language is the most important part of fulfilling this need. Writing simply demands that authors not just explain complex technical terms, but use simple terms at all times. This means using simple phrases (see Table 7.1 for some examples; there are many more), using the active voice (Table 7.2), keeping sentences short, keeping paragraphs short and avoiding jargon. It does NOT mean avoiding difficult subjects.

Table 7.1   Using simple words and phrases

Common expression	Simpler choice
• in relation to	• about
• assistance	• help
• at such time as	• when
• prior to	• before
• following	• after

Adapted from *Plain English at Work: Writing Tips* (DETYA 1999)

Table 7.2   Using the active voice

Passive expression	Active expression
Regular examination of the breasts is recommended.	The Anti-Cancer Council recommends regular breast examination.
Examination of the liver revealed it to be free of metastases.	There were no metastases in the liver.
A breast biopsy was performed on five patients.	Five patients had a breast biopsy.

Note: Other examples are given in *Medical Writing: A Prescription for Clarity* (Goodman and Edwards 1991).

7.1.2   Reading age

The readability or comprehensibility of any publication is important — particularly so for consumers. It is worth remembering that the language skills of people who are in a position to prepare health information for others is, in general, well above average.

Reading age scales are one way of determining the comprehensibility of any documents and there are a variety of scales that can be used to rate comprehension levels. These scales have mainly been developed in the United States and are objective (rather than subjective) methods based largely on the number of words per sentence and the proportion of words that have three or more syllables (polysyllabic). Clearly, words with one or two syllables are easier to understand, as are short sentences.

The SMOG scale (simple measure of gobbledegook), the Flesch scale and the Fog index (Ley and Florio 1996) are all validated methods of checking the reading level of a document and each is described in more detail in Appendix C. Draft consumer publications should therefore be checked using one of these scales to see whether the reading age is appropriate for the target audience.

However, it is not possible, based on data, to recommend the appropriate level at which to pitch most consumer documents because there has not been enough research on reading ages in the consumer population. The Anti-Cancer Council of Victoria, which produces an impressive range of consumer documents, aims to produce them with a reading age of 12, equivalent to a reading grade of 7 (D Reading, Anti-Cancer Council of Victoria, personal communication) (see Appendix C).

However, it is easier to produce a document at the appropriate reading age if those writing it keep a simple question in mind: 'Is this the way I would speak to my reader?'. Imagine someone with the condition you are writing about —

wanting to know everything, worried, perhaps well educated, perhaps not. Having such a target reader in mind will keep the language simple.

7.1.3   Numeracy

As with reading age, numeracy skills also vary greatly among consumers. Information on presenting risk information is given in Section 5. The issue of consumers' numerical skills and the challenges presented by low levels of numeracy were also discussed in detail in the literature search (see Introduction).

7.1.4   Expression

Clearly, all publications for consumers should be free of jargon and written in plain English. Any medical terminology should be reserved for a glossary, or should only appear after plain English explanations of the term. For example, 'you may then see a specialist in the treatment of cancer with radiation, who is known as a radiation oncologist' may be appropriate. It is easier and more efficient for health professionals to adapt to using plain English than it is for all consumers to adapt to using medical jargon.

Help with plain English is available through the Commonwealth Department of Education, Training and Youth Affairs. Its website includes a search facility for its reports and resources and a list of guides to plain English.[2]

7.1.5   Use of capitals

Minimise capitalisation. The use of too many capital letters is old-fashioned and can be intimidating to readers (DETYA 1999). For example, if you form a working party, it should be described as such, with the first letter of each word in lower case, rather than as a 'Working Party' with initial capitals. The convenor, chairperson, secretary and project officer can also all have lower case initials.

The first letter should also be lower case for ministers, general practitioners, nurses, and health care workers; even for specialists, such as obstetricians, neurologists and surgeons. This also applies to places — neonatal intensive care unit, birthing centre and operating theatre.

Reserve capitals for full formal titles such as Minister for Health and Aged Care, President of the Australian Medical Association or Queen Victoria Hospital Birthing Centre.

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[2] www.detya.gov.au/publications/plain_en/pepubs.htm

Similarly, keep italics and bold to a minimum.

7.1.6   Ambiguity

Avoid ambiguity by checking for double meanings. For example, the London Underground used to have signs saying: 'Dogs must be carried at all times'. This was not clear (DETYA 1999).

Medical writing often abounds with ambiguities. For example, does 'extra hepatic tumours' refer to additional tumours in the liver, or tumours at sites outside the liver?

7.1.7   Acronyms and abbreviations

Avoid acronyms and abbreviations, unless they are in common usage. For example, AFL (for Australian Football League) may be acceptable in a consumer document, where NHMRC would not. The term 'mL' may be an acceptable abbreviation for a unit of measure (millilitres) in some contexts, but 'kP' (kilopascals) is not. For some publications it may be advisable to put all such units in full.

Even where common acronyms and abbreviations are used, they should be spelt out in full the first time they are used in a publication.

7.1.8   Perspective

Publications written from the point of view of an individual ('you') may be received more warmly by readers than publications written from a less personal perspective. However, the individual perspective can be confronting when dealing with serious negative consequences, such as disability or death.

A common technique is to prepare the material in a personal way, and switch to an impersonal tone when dealing with difficult issues. For example, 'you are likely to need a week or two to recover from the operation' is personal and nonconfronting, but the impersonal tone is better for information such as 'about one in 50 people die as a result of the treatment'.

7.1.9   Interactive elements

In education, interactive approaches work better than didactic ones.

Computer-based publications, especially those using CD-ROMs, are capable of leading consumers through a variety of options, and of presenting a range of materials depending upon the age or circumstances of the consumer.

Print-based materials can also introduce interactive elements through the use of diaries and charts, symptom records, questions, checklists and blank space.

7.2   Design of printed publications

People spend years learning about design. It is therefore advisable to employ a professional designer for consumer publications. Whether working with a designer or producing a publication inhouse, however, the following tips may be helpful.

7.2.1   Type

Hundreds of typefaces are available. Some are easier to read than others — a simple and easy to read typeface should always be chosen.

Serif and sanserif typefaces are available. Serif typefaces have 'tips' on the end of each stroke of a letter, while sanserif typefaces do not.

$$k \quad k$$

Serif typeface (Times New Roman) on left, sanserif (Arial) on right.

Serif type is easier to read than sanserif type (DETYA 1999). In general, longer documents use serif types, which are more traditional, and briefer documents such as pamphlets and magazine articles use sanserif type.

With the availability of different typefaces on computers, it is tempting to use a variety. However, too great a variety of typefaces is confusing. No more than two or three typefaces should be used per document. A common technique is to use serif type for the text and sanserif type for the headlines and captions.

Lower case letters are easier to read than capitals. Where emphasis is required, bold type is read more easily than capitals or italics.

Type is measured by the height of lower case letters, and it is measured in points. There are 72 points to an inch. Type should be no smaller than 10-point in size. Anything smaller is difficult to read.

Leading (pronounced 'ledding') is the space between the lines. In general, leading should be about 120% or greater, meaning that 10-point type should have at least 12-point leading, and 12-point type should have 14.4-point leading.

Any publication for the visually impaired should be in 14 or 16-point type (RNIB 1997).

7.2.2   Paper

Matt surfaces are easier to read than glossy surfaces because they reduce reflected light (RNIB 1997). However, gloss art papers give sharper reproduction of illustrations and colour. Documents containing mainly text should by published on matt paper, while illustrative documents should be published on gloss art.

Paper should be thick enough to stop material on the reverse showing through. The minimum weight of paper recommended is probably 90 gsm (grams per square metre).

7.2.3   Illustrations

Illustrations (including charts, pictures, tables and boxes) are a vital part of a consumer document. They explain anatomy, show tools used, break up text and enhance readability by complementing text.

Quite importantly illustrations can also be used to explain complex issues such as risk. *Making Choices: Hormones after Menopause* (O'Connor et al 1996) provides clear examples of how illustrations explain risk (see Appendix D).

7.2.4   Justification

Alignment, or lack of alignment, of the edges of a block of text, is termed justification. Text that has a straight left-hand edge, but is uneven on the right, is not justified. Text which is justified has straight edges down both sides.

Unjustified text is easier to read and understand, as justification distorts the spaces between words (and sometimes letters), making them uneven. Although usually treated as a matter of design, justification affects comprehensibility.

7.2.5   Margins and white space

Margins should be generous. Larger margins increase a text's readability.

The generous use of white space between paragraphs, with margins and good use of headings and subheadings, enhances readability.

7.2.6   Breaking text up

Text should be presented in fairly small sections, with a number of headings and subheadings. This allows readers to stop and start more readily, and

encourages a sense of the important messages in a publication. It is also easier on the eyes.

7.2.7   Colour

Colour enhances the appeal of any publication, while increasing its cost. Basic printing machines take one or two colours while a four-colour machine prints all colours. Using one colour is cheapest, while two colours increases costs slightly. There is a larger jump in cost when a four-colour machine is used.

Text is easier to read if:

- its colour contrasts greatly with that of the paper;

- it is dark on a light background; and

- it is of one colour.

Light text on a dark background should be reserved for small amounts of text, such as headlines and captions.

7.2.8   Keeping the design in the background

Unlike poor design, good design is barely noticed. It allows you to concentrate on the text without distraction. Common design problems include:

- a cluttered design, which makes the reading order unclear;

- mixed typefaces, which make the document look messy and confusing;

- a lack of headings or boxed summaries, so the reader needs to scan the entire document to find the information they want; and

- inappropriate cartoons, which appear to make fun of a serious subject (DETYA 1999).

7.3   Consumers' views

Based on focus group discussions with 62 people, Coulter et al (1998) developed a table of consumer likes and dislikes of presentation issues (Table 7.3). This table may be biased towards the more proactive type of consumer, as focus group participants were recruited by advertisement; nevertheless their comments should be helpful.

Table 7.3   Consumer likes and dislikes in consumer publications

	Likes	**Dislikes**
Tone/mood	Positive, hopeful, encouraging, cheerful, optimistic, reassuring, constructive, nonalarmist	Negative, off-putting, stresses all the things that 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 and possible after effects, overoptimistic, misleading, disinterested, written by someone just doing a job, patronising, talking down to you, childish, dismissive in tone, flippant, judgmental
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
Language/readability	Clear, easy to read, easy to understand, plain speaking, simple, straightforward wording, spells out the terms, puts more clinical words in brackets	Complicated language and explanation, too technical, badly written
Structure	Structured and concise, clear headings, sections allow you to dip in and out, succinct, important sections highlighted, short blocks of text, well indexed	Jumbled up, slabs of text, dense text, too long
Layout	Large print, uncluttered, not filled with print, nice mix of drawings and print	Small print, hard to read, unattractive layout, boring presentation
Overall impression	Professional looking production	Drab, cheap, amateurish, appearance of cost-cutting

Source: Coulter et al (1998)

Key points — presentation

1. Consumer publications should appropriately target the literacy skills ('reading age') of the target audience, with simple language, short words and sentences, clear expression and explanation of difficult concepts (such as risks and benefits).

2. The design should enhance readability through use of clear typefaces, helpful illustrations, appropriate breaking up of the text, use of white space, judicious use of colour and other design features.

APPENDIX A

MEMBERSHIP OF PRODUCTION TEAM FOR HANDBOOK

NHMRC Assessment Panel

Professor Paul O'Brien (Chair)	Department of Surgery, Monash Medical School Member of HAC
Professor Chris Silagy	Monash Institute of Public Health and Health Services Research Member of HAC
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Secretariat

Ms Roz Lucas, Ms Janine Keough, Ms Monica Johns	Health Advisory Unit, Office of NHMRC

APPENDIX B

PROCESS REPORT

During the 1997–99 NHMRC triennium the Health Advisory Committee focused its work on the areas of coordination and support rather than on collating and reviewing scientific evidence. However, the committee recognised that a key part of its coordination and support function was to provide a methodology on how to develop evidence-based guidelines.

The NHMRC publication *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1999), which had been produced by the Health Advisory Committee as a resource for people wishing to develop clinical practice guidelines to a standard acceptable to the NHMRC, was revised during 1998. Early in the revision process, the committee realised that there was a need for a number of complementary handbooks to expand on the principles outlined in the document. This complementary series would cover other aspects of the identification, collation and application of scientific evidence. It was envisaged that these handbooks would be of invaluable assistance to agencies wishing to develop clinical practice guidelines of a high standard either independently, or on behalf of the NHMRC.

It was agreed that there would initially be five handbooks in the series:

- how to review the evidence;
- how to use the evidence;
- how to put the evidence into practice;
- how to present the evidence for consumers; and
- how to compare the costs and benefits.

They would be published individually to allow flexibility in their production and revision, as well as to allow any later additions to the series.

Recognising the need for a transparent and competitive process for contracting the services of an expert(s), tenders were sought for the preparation of each handbook. A selection committee was then appointed by the Health Advisory Committee to consider the tenders.

Once the successful tenderers had been contracted to prepare the handbooks, an assessment panel, composed of Health Advisory Committee members, was formed to manage the progress of each project (see Appendix A).

When first drafts of each handbook were received, they were distributed to a small number of experts in that particular field for peer review. The documents were subsequently revised in the light of these comments. A technical writer was employed to ensure consistency in content and style within and between the handbooks.

The finalised documents were referred, in turn, to the Health Advisory Committee for approval before being forwarded to the NHMRC for endorsement.

APPENDIX C

ASSESSING READING SCORES

It is sometimes assumed that the 'reading age' of a text signifies the age at which a majority of children should be able to read that text quite easily. This is not true of many of the reading age scales developed.

In fact, the reading age for most scales, including the Fog index and the Flesch scale described below, is the age at which an average child will comprehend 50% of the text. So if you have a document with a reading age of 14, half of all 14-year-olds will comprehend half of it or more. And half of all 14-year-olds will comprehend less than half of it. In fact, the majority of 14-year-olds would either not understand, or barely understand, a text with a reading age of 14.

The implication is that comprehension can be increased by aiming below the reading age of the majority of the target audience. People find texts easier to read that are pitched two years below their reading age (Klare 1963).

It is possible to assess the reading scores of any text by using one of 200 or more scales which have been developed. Three of the most commonly used scales will be described below — the SMOG scale, the Flesch scale and the Fog index. They are said to be accurate to within 1.5 years.

Most of these scales have been developed in the United States, and originally gave a reading *grade* (a school grade) based on starting school at five years of age. So to give a reading *age*, five years are added.

Fog readability index

Take three samples, each of 100 words. Estimate the number of sentences to the nearest tenth, where necessary. Then:

$$\text{Reading age} = [(L + N) \times 0.4] + 5$$

where:

L = the average sentence length (number of words ÷ number of sentences)

N = the average number or words of three or more syllables per sample

The Fog readability test is suitable for secondary and older primary age groups (Gunning 1973).

Flesch scale

Take three samples, each of 100 words. Estimate the number of sentences to the nearest tenth, where necessary. Then:

$$\text{Reading age} = (L \times 0.39) + (N \times 11.8) - 10.59$$

where:

L = the average sentence length (number of words ÷ number of sentences)

N = the average number of syllables per word (number of syllables ÷ number of words)

This test is available on many word-processing software packages, such as Microsoft Word 97.

SMOG scale

SMOG stands for the simple measure of gobbledegook.

For texts with more than 30 sentences:

- take three samples (from beginning, middle and end of the text) each of 10 consecutive sentences
- count all the words containing three or more syllables
- estimate the square root of that number
- add eight

For texts with fewer than 30 sentences:

- count all the words containing three or more syllables
- count the number of sentences
- find the average number of polysyllabic (three or more syllables) words per sentence
- multiply that average by the number of sentences
- add that figure on to the total number of polysyllabic words
- find the square root
- add eight

It is possible to do a quick version of the SMOG test. Count the number of polysyllabic words in a chain of 30 sentences and look up the approximate grade level on the SMOG conversion table, set out below.

In using these formulae:

- hyphenated words count as one word
- numbers should be considered as if they are spelt out
- abbreviations should be considered as if they are spelt out

SMOG conversion table

Polysyllabic word count	SMOG reading age
0–2	9
3–6	10
7–12	11
13–20	12
21–30	13
31–42	14
43–56	15
57–72	16
73–90	17
91–110	18
111–132	19
133–156	20
157–182	21
183–210	22
211–240	23

Source: United States Department of Health and Human Services (1992)

APPENDIX D

CASE STUDIES

Case study 1
Hormones after menopause

Making Choices: Hormones after Menopause (O'Connor et al 1996) is a decision aid for women developed by the Ottawa Health Decision Center, which is part of Ottawa Civic Hospital in Ottawa, Canada.

It comprises three parts — a 45-minute audiotape, a 26-page A5 booklet and a fold-out chart.

The booklet

The booklet explicitly targets postmenopausal women who:

- are on hormone replacement therapy (HRT) and wondering whether to continue;

- have used HRT before and are wondering whether to start it again; and

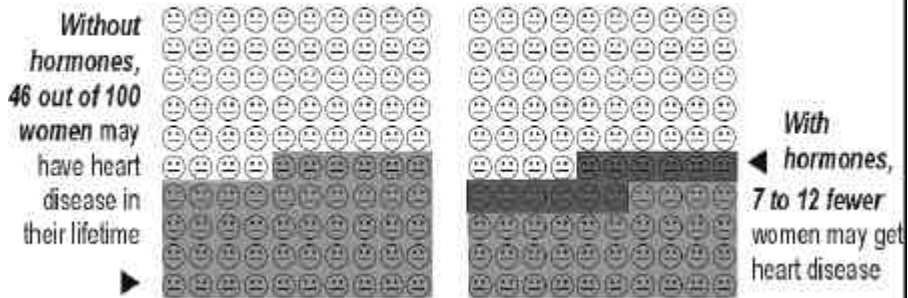- have never used HRT before and are wondering whether to start.

It describes the potential risks and benefits of HRT.

It gives details of the symptoms, causes, risk factors and management of problems affected by HRT, such as heart disease.
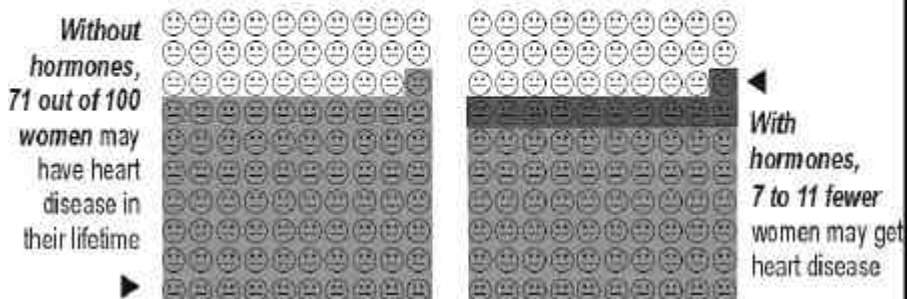
It uses clear illustrations to help explain how HRT can increase the absolute risk of one condition (breast cancer), while reducing the absolute risk of another condition (heart disease and osteoporosis). An example of the illustration used to show risk is shown below (Protection from heart disease as a result of hormone replacement therapy). It then gives women directed questions which allow them to weigh up their own benefits and risks, also shown below.

Protection from heart disease as a result of hormone replacement therapy

The "average" 50 year old woman

Without hormones, 46 out of 100 women may have heart disease in their lifetime ▶

◀ *With hormones, 7 to 12 fewer women may get heart disease*

The "high risk" 50 year old woman

Without hormones, 71 out of 100 women may have heart disease in their lifetime ▶

◀ *With hormones, 7 to 11 fewer women may get heart disease*

Source: Reproduced with permission from O'Connor et al 1996

Six steps to weighing up my own risks and benefits.

1. What are the possible risks and benefits for me?

    - What is my risk of heart disease and osteoporosis?
    - How much will hormones increase my protection?
    - Do I need relief from menopausal effects?
    - What is my risk of breast cancer?
    - How much will hormones increase my risk?
    - How will I respond to side effects?
    - Do I have other concerns that mean I should not take hormone therapy?

2. How important are the risks and benefits to me?

    - The extra protection from heart disease?

    - The extra protection from osteoporosis?

    - Relief from menopausal effects?

    - The extra risk of breast cancer?

    - The side effects?

    - Other concerns?

3. What else am I doing to promote healthy bones, heart and breasts?

4. What questions need answering before deciding?

5. Who should decide about hormones?

6. What is my overall leaning about taking hormone therapy?

Finally, it gives sample responses from four women in different circumstances, then lists suggested further reading.

The audiotape

The audiotape is an accompaniment to the booklet. For some, it would be the main source of information, for others it would be a guide to the booklet.

The audiotape expands on the material covered in the booklet, especially in the areas of risk factors and self-help. It explains the illustrations and guides readers through them.

The audiotape also introduces new information, describing the process of clinical trials and the weight that can be given to nonrandomised trials.

The language used in the booklet is far less complex than that used in the audiotape.

The fold-out chart

The fold-out chart has six sections.

The first section covers personal benefits — protection against heart disease and bone disease, and relief of menopause symptoms. It then covers personal risks — breast cancer, menstrual and hormone history — and other concerns.

With both benefits and risks, it asks readers to quantify their individual risk factors or symptoms. It also uses the illustrative style of the booklet (see above) to show the potential gains in benefit and risk that HRT can bring about.

The second section is headed 'my values'. It takes the information gathered in the first section a step further and directs readers to ask themselves how important each of these factors is.

Section three discusses other things that women can do to improve or maintain their health, but in a personal way. It asks: 'Am I taking the following steps?'

- maintaining healthy blood pressure;

- exercising regularly;

- not smoking;

- lowering stress; and so on.

Section four has a space for 'my questions'.

Section five asks: 'Who should decide about hormones?' and gives three options — the woman, the practitioner, both or unsure.

Section six is a visual scale, with 'yes to hormones' at one end and 'no to hormones' at the other. The section is headed 'my leaning'.

An example of the use of the chart is shown below in 'Mary's situation'.

The result

The result is that women deciding whether or not to take HRT are guided through a series of steps. These are:

- the objective risks and benefits of a treatment;

- the subjective impact of these risks and benefits;

- the notion that there are other options apart from this treatment; and

- the decision — whether to be taken alone, shared with a health practitioner or taken by the health practitioner.
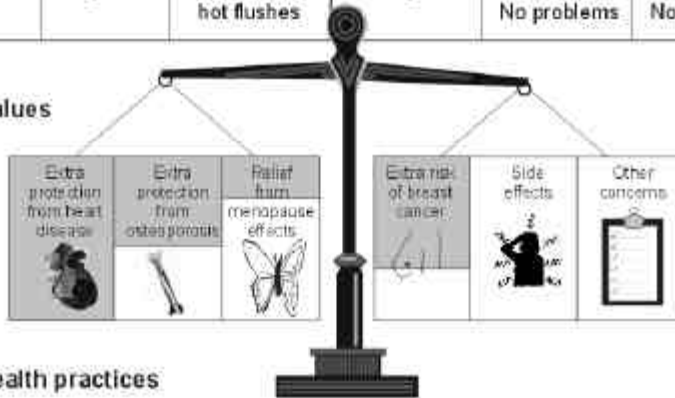
Steps for consumers to weigh benefits and risks

Mary's situation

1 My possible benefits & risks

Heart	Bones	Menopause	Breast	Hormone history	Other concerns
High risk	High risk	Bothered by hot flushes	Average risk	No problems	None

2 My values

Extra protection from heart disease | Extra protection from osteoporosis | Relief from menopause effects

Extra risk of breast cancer | Side effects | Other concerns

3 My health practices

Exercise regularly
Not getting enough calcium

4 Questions

What else can I do to protect myself from breast cancer?

5 Who should decide?

My practitioner and I should decide together

6 My leaning

✓									

Yes
Hormones   Unsure   No
Hormones

Evaluation

The *Making Choices: Hormones after Menopause* decision-support package has been evaluated by randomised controlled trial in 165 postmenopausal women considering HRT. The trial was methodologically of very good quality. For example, it used centralised random allocation to study groups to ensure the groups were comparable at baseline, follow-up was complete, and, although the outcomes were based on self-reported data, the analysis was done 'blind' to the study group status of each participant. The outcome measures included knowledge, expectations of risks and benefits, an assessment of how difficult the decision was, and the decision to take (or not take) HRT.

The group given the decision-support package experienced less difficulty arriving at a decision and had more realistic expectations of the risks and benefits of HRT. Knowledge was the same for both groups and 58% of both groups declined HRT. Thus it appears the decision-support package did not influence the decisions these women made, but it did make the decision process easier and improved the accuracy of their expectations of treatment with HRT.

Case study 2
Benign prostatic hyperplasia

Benign Prostatic Hyperplasia: Choosing Surgical or Nonsurgical Treatment. A Shared Decision-Making Program is a one-hour video produced by the Foundation for Informed Medical Decision Making, in Hanover, New Hampshire in the United States.

It explicitly states its target group — men with benign prostatic hyperplasia but not men with prostatic cancer, urinary tract bleeding, recurrent urinary tract infections or a host of other conditions. It states that it should only be used in 1998, which suggests it will be updated, or at least reviewed regarding the need for update, annually.

It also states its sponsors clearly, although the nature, background and purpose of the Foundation for Informed Medical Decision Making may not be clear to the average consumer.

The video is explicit in its purpose — it aims to encourage shared decision making. This may make viewers who want their doctors to make the decision, or who want to make the decision themselves, uncomfortable.

The video, which is accompanied by a small booklet, explains the choices a man with benign prostatic hyperplasia may make. The choices are divided into surgical, with a range of types of surgery described, non-surgical, which

comprises 'watchful waiting' (regular check-ups but no actual treatment) and drugs.

The video shows interviews with three patients who have different experiences of benign prostatic hyperplasia. Unfortunately, all three are doctors (two are former professors), so they hardly reflect the common consumer.

It also describes, using fairly simple numerical concepts, the risks and benefits of each treatment. For example, it says that four in 1000 men who have prostatectomy will die within weeks of the operation. It also adds that 'this means 996 will survive', and that 'not all these men died because of surgery —

The information presented is balanced, and does not push the viewer towards any single option.

However, it only presents information. It does not raise any issues about personal feelings, fears or desires that may help viewers make decisions.

Evaluation

A formal evaluation of the video alone is not available. However, a more complex decision-support package, based on this video plus an interactive computer program, has been evaluated in a longitudinal study of 373 men with symptomatic benign prostate disease. The interactive element allowed for review of material and presentation of new material in the form of additional optional modules. These provided more in-depth information on sexual dysfunction and incontinence after surgery, how prostate surgery is done, the relationship between benign prostatic hyperplasia and prostate cancer, and the use of blood products in surgery.

Ten per cent of the men underwent prostate surgery in the following three months. Seventy-seven per cent of participants rated the decision-support package very positively as an aid to making a treatment decision. The study also examined the men's decision-making processes, and found that men were more likely to choose surgery if symptoms were severe and if they rated those symptoms very negatively, and less likely to choose surgery if they rated the possibility of becoming impotent after surgery very negatively. This suggests that consumers' attitudes to current symptoms and potential risks of treatment are very important in decision making and supports the value of shared clinical decision making.

ACRONYMS AND ABBREVIATIONS

DETYA   Commonwealth Department of Education, Training and Youth
               Affairs

HRT   hormone replacement therapy

NHMRC   National Health and Medical Research Council

NSAID   nonsteroidal anti-inflammatory drug

P-value   probability (see Table 5.1)

SMOG   simple measure of gobbledegook (method for assessing reading
               age of written text)

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