

Human
Services



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Communicating with
Consumers Series Volume 1

Well-Written
Health Information:
A Guide

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Acute Health

Well-Written Health Information: A Guide

Kay Currie, Janet Spink and Meera Rajendran.

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Effectiveness Unit
Quality and Care Continuity Branch
Acute Health Division
Department of Human Services
555 Collins Street
Melbourne Vic 3000
Australia
Ph: (03) 9616 7324

Acute Health

Well-Written Health Information: A Guide

Prepared for the Department of
Human Services by the Centre for
Clinical Effectiveness and Health
Issues Centre

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Project Directors: Jeremy Anderson and Meredith Carter

Centre for Clinical Effectiveness,
Monash Institute of Public Health

Jeremy Anderson, *Director*

Kay Currie, *Project Manager*

Meera Rajendran, *Researcher/Information Officer*

Health Issues Centre

Meredith Carter, *Executive Director*

Janet Spink, *Researcher/Policy Worker*

Foreword

This Guide is the first in a series of reports from the Assessing the Quality of Consumer Information Project carried out by the Centre for Clinical Effectiveness, Monash Institute of Public Health and the Health Issues Centre, Melbourne. The Project was funded by the Effectiveness Unit, Quality and Care Continuity Branch, Acute Health Division, Department of Human Services Victoria.

The Project was based on the King's Fund study *Informing Patients: An Assessment of the Quality of Patient Information Materials* (United Kingdom 1998). The Project assessed the quality of written consumer information in six health conditions using input from consumers, clinicians and publishers. The evidence base of the information and its relevance to consumers

during the assessments. This Guide is a distillation of the findings of the Project on the preferred format, content, presentation and language necessary in a quality publication.

This Guide is best read in conjunction with the other reports in the *Communicating with Consumers* Series. This series includes reports on written information about:

- Chest Pain
- Cholecystectomy
- Mastitis
- Menorrhagia
- Pain Relief During

Childbirth

- Stroke
- An Analysis of the

State of Consumer Health Information Provided by Public Hospitals in Victoria.

The Guide is in two sections. Part A is an introduction. Part B is the guide to producing consumer health information and

checklist to assess the quality of information.

We would also like to acknowledge and thank all those consumers, clinicians and health care providers throughout Victoria who contributed so generously to the success of this project.

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Introduction

This Guide is based on the findings of the Assessing the Quality of Consumer Information Project, undertaken between August 1999 and June 2000 for the Department of Human Services Victoria. The development of the Guide involved consumers, clinicians, publishers and exhaustive searching of the biomedical literature. It included critical appraisal of the best available evidence about treatment options using the criteria defined by the National Health and Medical Research Council (NHMRC, 1998).

The Guide assists health practitioners to work with consumers to design written health information. The aim is to ensure the information meets consumer needs, is comprehensive and is presented in an unbiased way. The Guide concentrates on written consumer information, as this is the most common way that consumer and practitioner discussions regarding treatment are augmented.

There are many other ways to provide information and sometimes alternative methods may be more appropriate. Written information may be best used as part of a package of information.

The Guide extends the findings of other publications addressing these issues (see Bibliography). It is informed by an Australian consumer perspective, reinforcing the critical role that consumers play in the planning, development, dissemination and evaluation of consumer health information. The Guide acknowledges the importance of the process of developing consumer health information and reinforces the important role of information based on evidence. The Guide is derived from the integration of both qualitative and quantitative research.

The objectives of consumer information products and the needs of consumers depend on a wide range of variables. There is no definitive checklist for producing consumer information—this Guide should be tailored to suit specific needs and circumstances.

The following sections highlight some important issues to consider when planning to produce and provide written information to consumers.

Introduction

1. Identify Key Stakeholders

It is important that the interests of all stakeholders are represented in the production of written consumer health information.

Ensuring all stakeholders are involved in, and committed to, the process may be time consuming and demanding, but the investment will be worthwhile. The end product will be information that meets consumers' needs and has the support of health practitioners and the health service. This will encourage its adoption and use, and ensure that the stakeholders are prepared to repeat the process to produce more consumer information as required.

Producing good quality consumer information is a collaborative process. This may involve conflict, negotiation and the sharing of very different points of view. There are many reasons why various stakeholders want to be involved in the production of health information. Some of the reasons are outlined below.

Reasons for Stakeholder Involvement

Consumers need:

- To participate in decision making regarding treatment.
- To be able to identify symptoms of a condition.
- To be able to prevent a condition developing or deteriorating.
- To be able to care for somebody with a condition.
- To know or understand what is happening to them.
- Information about self-help groups and contacts.
- Information about self-care and coping strategies.
- Assistance with asking questions when they are anxious or afraid.
- To participate more broadly in health service planning and development.

Health practitioners need:

- To assist with responses to consumer questions.
- To inform and educate patients about their condition.
- To obtain informed consent.
- To encourage consumers to ask questions and participate in the decision making process.
- To encourage consumers to comply with medications, treatment and recovery plans.
- To increase consumer awareness of risks and prevention strategies.

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Health service administrators need:

- To foster better partnerships with the community.
- To assist consumers in understanding and sharing more fully in their treatment decisions and health care plans.
- To assist consumers to use services more effectively, promoting better health outcomes and better use of resources including less reliance on defensive medicine practices.
- To promote services available through their organisation.
- To develop good information as part of their quality improvement programs.

Community health centres need:

- To foster closer relationships with other health and community services and the community.
- To improve the quality of care provided, particularly in relation to the transition from hospital to community care.
- To assist consumers to maximise the effectiveness of their treatments, medications and rehabilitation.

2. Consumer Involvement

Health care consumers are users, or potential users, of the health care system, as are their carers (families and support people). Though consumers may be experts in their condition in terms of how they feel and experience it, they still rely on the clinical expertise and experience of the practitioners responsible for their care. This needs to be recognised in both the treatment and information giving process when planning health care, and when producing consumer information.

Increasingly, consumers want to talk with health care providers about issues such as diagnosis, treatment, care planning, recovery or prevention. This is supported by the principles of the Public Hospital Patient Charter (see below).

Consumers also seek involvement in health services at many levels: strategic planning, policy development, service design, providing feedback, general community awareness and education about services, volunteering and fund raising, and one to one discussions between consumer and clinician (NHS, 1993; Silburn, 2000).

Agencies need to identify the specific purpose of consumer and community involvement and select strategies to promote it. When seeking input to develop consumer information, strategies to involve consumers may include consultation with peak consumer organisations and special interest groups, surveys of population groups and services users, focus groups and analysis of complaints.

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Providing consumers with accurate, comprehensive and understandable information can help ensure that they are able to participate more actively in their care and treatment. Research demonstrates that when consumers feel more in control of their treatment they experience better health outcomes (Renhard, 1997). This collaborative relationship benefits all parties and is likely to increase both practitioner and consumer satisfaction.

The Public Hospital Patient Charter Principles (draft)

You have the right to:

- * A wide range of public hospital services.
- * Treatment based on clinical need regardless of ability to pay or health insurance status.
- * Treatment and care in a safe environment.
- * Access your health records and confidentiality for your personal information.
- * Participate in making decisions about your treatment and care.
- * Participate in decisions and receive information about your discharge from hospital.
- * Treatment with respect, dignity and consideration for privacy.
- * Choose whether you wish to have treatment as a public or private patient.
- * Information about which hospital staff will provide your care.
- * Information about your health care and, if you wish, a second medical opinion.
- * Information on what steps the hospital takes to improve quality of care.
- * If necessary, access to an accredited interpreter.
- * Services provided in a culturally sensitive way.
- * An opportunity to discuss any questions or complaints you may have concerning your stay in hospital.
- * To make a complaint to an independent complaints body.

You have a responsibility to:

- * Work with your treating team by providing relevant information about your health or circumstances which may influence your treatment, recovery or stay in hospital.

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3. Evidence

Evidence-based patient information should centre on questions that have been identified by consumers as important in helping them make choices about their treatment. The more information consumers have about their condition or treatment options, the better they will be able to identify any further information they need and any issues they need to discuss with their treating team.

Evidence in health care is not static. It is constantly changing and evolving. Within an evidence-based paradigm, not all evidence is considered equal. Evidence is classified using 'levels of evidence'. The level accorded to the evidence is an indicator of the degree to which bias has been eliminated by the study design. The quality of the evidence can be determined by critical appraisal of the literature. Searching for the evidence and critically appraising it can be time consuming and laborious.

Providing consumers with evidence about treatment outcomes (the benefits and risks) may help them make decisions about their treatment. Consumers are interested in quality of life, care processes and clinical outcomes. However, evidence-based consumer information should not be used to 'push' certain treatments. Consumer information needs to include all treatment options available and be presented in an unbiased manner, including the option of no treatment or 'watchful waiting'. There are numerous areas in health care where there is a lack of evidence that can be classified at the highest level or addresses process or quality of life issues for consumers. Consumers need to be informed of the gaps or uncertainties in the evidence.

4. Process and Content

Producing written consumer information is not only about the content of products, such as pamphlets; it is also about the process of producing that information. A relatively small percentage of available resources is used in the actual writing of the product. Most of the resources need to be applied to planning, searching and appraising the evidence, evaluation, dissemination and ongoing maintenance of the written information. Key stakeholders, particularly consumers, need to be involved at all stages of the process.

The 'shelf life' of much written consumer information is short, due in part to the changing needs of consumers and the dynamic nature of research. This can result in relatively high production costs and lowered economies of scale.

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5. Implementation of Guides

Guidelines or guides are documents intended for practical application, however, they are notorious for not being implemented. There are several possible explanations: it may be that the people for whom the guides are intended were not involved in the process; they do not perceive the need for the product; the task is too complicated; there are insufficient resources; there is limited time; or there is no identified person with the primary responsibility to implement the guide. These issues are similar in the production and use of consumer information and also need to be considered when producing consumer health information.

6. Dissemination

Dissemination of consumer information needs to be a routine part of health service delivery. This can only be achieved with the support of management and decision and policy makers committed to the dissemination process.

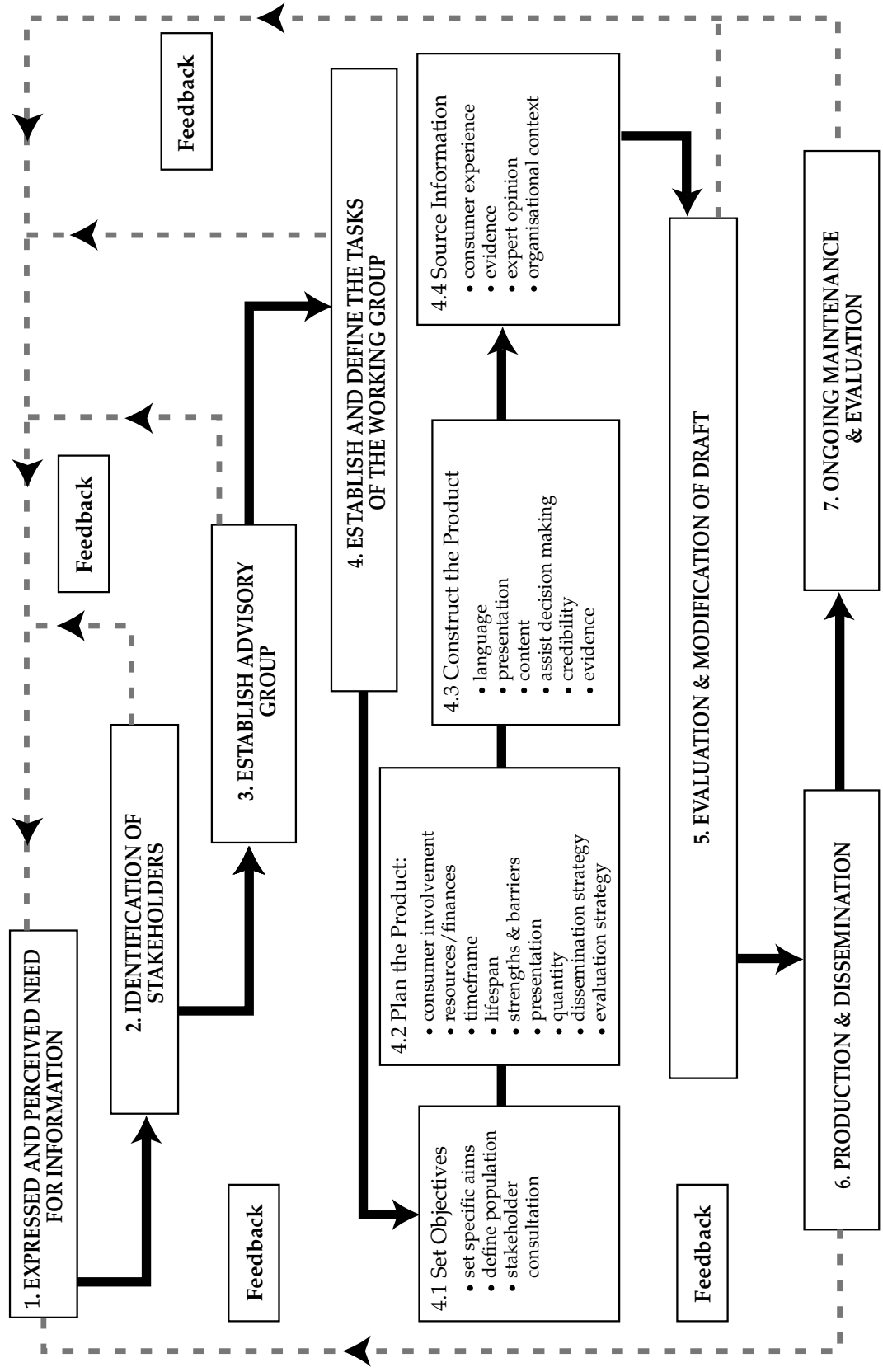
Consumers report that the best way for them to receive written or printed information is through a supportive and trusting relationship with health practitioners, underscoring the key role of practitioners in dissemination strategies.

The timing of information is particularly important because consumers will be receptive to different types of information at different phases of their diagnosis, treatment and recovery.

7. Maintenance and Review

Updating written information and ongoing review of its reliability requires significant organisational commitment. Changes in staff, restructuring and resource allocation will affect the ongoing relevance and credibility of consumer information products. The production budget will need to include a component to cover these costs for a specified timeframe.

8. Producing Written Consumer Health Information



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1. Need for Written Consumer Information

Consumer information is produced as a result of an expressed or perceived need. The need may be expressed directly by consumers, or it may come from health practitioners, health service administrators or community health services, in response to questions their consumers ask or information consumers may need to know.

There needs to be some consistency and integration of information produced by different sources within a health facility to reduce duplication and confusion amongst consumers. It is therefore important to be aware of any existing consumer information sources that already meet the needs of consumers and to develop a policy for ensuring consistent use within an agency.

2. Identify Stakeholders

Stakeholders need to include consumer representatives, administration and management representatives, health practitioners and community organisation representatives.

2.1 Consumers

- Consider a mix of consumer representation. Consumer representatives may be recruited from those who have either used the health service and/or experienced the health condition; a consumer organisation concerned with the condition; and/or a consumer health advocate. They need to be people who are willing and able to represent a consumer perspective. Consideration should also be given to carers.
- Encourage active consumer participation at each stage of the process.
- Implement strategies to encourage consumer representatives to consult with a wider network of consumers throughout the process. For example, develop links with a supportive consumer advisory group, conduct consumer surveys or focus groups and interview individuals.

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2.2 Key Providers, Health Service Administrators and Managers

- Include key providers from the relevant departments, for example, departmental heads/directors, heads of nursing, and relevant people from allied health, to ensure acceptance and dissemination of the product.
- Include key administration people from the health service to ensure funding, health service support and dissemination, for example, quality manager, in-house publication department and finance department.
- Include a patient advocate or patient representative.

2.3 Key Community Organisations

- Involve relevant community organisations such as self-help groups or disease-specific foundations.

3. Establish an Advisory Group

The advisory group would include stakeholders who will provide organisational clout, political support and resources. This group may form the nucleus of the actual working group that will undertake the practical tasks involved in developing written consumer information and reporting to, and consulting with, the advisory group. It is important to ensure the working group maintains representation of all the key stakeholders. The advisory group should develop an ongoing assessment, evaluation and review strategy as part of the planning process.

4. Establish and Define Tasks of the Working Group

The working group needs to include people with practical involvement such as clinicians and consumers. It needs to be reasonably small to operate effectively and membership will vary according to the aims and objectives of the task.

With different interests represented around the table, it is likely that views will differ about what needs to be included, how material will be presented and so on. It may be helpful to discuss this at the outset, and to acknowledge that some conflict may arise during the course of the project. If the various perspectives and concerns can be discussed openly, the group will be able to work through these differences and achieve a better product as a result. To assist with this, groups might find it useful to agree on some core principles to guide the development process. These might include a commitment to: actively involving consumers and meeting their needs; providing a comprehensive overview of treatment options; and basing written information on the available evidence and best clinical practice.

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4.1 Set Objectives

- Identify the specific objectives of the written information.
- Identify the target audience.
- Decide on the objectives within the working party and in consultation with the groups represented.

4.2 Plan the Product

- Clearly articulate the commitment to involve consumers in all steps of production.
- Obtain a financial commitment from the health service to publish the product.
- Allocate time and resources for its construction, dissemination and evaluation.
- Be aware of the implications if the written information is being funded by a particular interest group, for example, a pharmaceutical company.
- Identify the organisational strengths that will assist in completing the task.
- Identify the organisational barriers that may impede the task.
- Consider the intended presentation including the:
 - Format
 - Layout
 - Colour
 - Diagrams, photography, illustrations
 - Translation into other languages
 - Cross-cultural sensitivities.
- Plan the dissemination strategy, including some estimation of the quantity of pamphlets or brochures required and possible points of distribution additional to the consumer–clinician consultation itself.

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4.3 Sources of Information

4.3.1 The Consumer Experience

The important questions to address will include:

- What are the consumer experiences with regard to the condition?
- What are their particular concerns?
- What questions should the written information prompt consumers to ask?
- How are the answers to the concerns or questions best presented?

There is a range of strategies to discover what the consumer experience has been and how it might be improved. These strategies might include involving consumers in focus groups; surveys and individual interviews; and consultations with consumer organisations and self-help groups.

4.3.2 Search and Appraise the Literature

This requires a systematic search for the evidence and a subsequent critical appraisal of the literature ⁽¹⁾. This task involves:

- Identifying all the evidence available.
- Classifying the evidence according to the study design and methodology.
- Critically appraising the evidence to ensure consumers are being provided with quality information.
- Identifying information that is balanced and includes both the benefits and risks.
- Identifying controversies and gaps in the evidence.
- Providing evidence of how treatments or diagnostic tests compare with each other wherever possible.

4.3.3 Expert Opinion

Clinical experts provide:

- Information about current clinical practice.
- Information about the availability of clinical services.
- Experiential insight into clinical practice, for example, adverse outcomes.

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4.3.4 Organisational Context

The working group needs to determine:

- What services are available to meet the needs expressed in the written information for particular medical conditions. For example, if the written information suggests that best practice is delivered by a stroke unit, does the organisation have a stroke unit or is treatment provided in a general medical ward?
- Organisational policy about referring consumers to other agencies which provide the services or treatments it does not offer.
- Organisational policy about copyright of the written information produced.

4.4 Construct the Product

There are many pitfalls to be avoided in developing written consumer health information. These points underscore the usefulness of pilot testing any product before engaging in wider dissemination. However, some general principles likely to enhance the construction of the product include:

- *A variety of information products may be required* • Consumers and clinicians have identified the need for different information to be provided at different times during the course of diagnosis, treatment and recovery. This has implications both for the design of written information and whether one or more information products need to be developed.
- *Cultural sensitivity* • It is important that written information can be read and understood by the range of communities that use a health service. This may be difficult to accommodate in a generic pamphlet. It may mean that more specific written information may need to be developed to respond to the particular cultural and linguistic nuances of different consumer groups. The resource implications inherent in this suggest that collaboration between a group of providers serving specific populations or community groups may be a cost-effective approach.
- *Avoid oversimplification* • Often the written information that consumers are given is so brief that they misunderstand it and/or inappropriately self-medicate. In other cases, the appropriate terminology is not used or an inadequate description of the condition, treatment or procedure is given resulting in ambiguity.

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- **Construction of the product.** • The following headings can help to structure your product:
 - Language
 - Presentation
 - Usefulness and content
 - Helping decision making
 - Credibility
 - Evidence.

These issues are discussed below.

4.4.1 Language

- Jargon, acronyms, technical and medical terminology are best avoided. If they need to be used, they will be more acceptable if accompanied by a straightforward definition, including advice on how to pronounce such terms.
- To ensure the widest audience, the information needs to be comprehensible to people across a wide range of literacy skills. Short sentences that are straightforward and easy to read will aid comprehension. The tone of written information also needs to be responsive to the diverse characteristics of the audience. Knowing the demographic characteristics of the intended population will help to design an appropriate product in terms of level of language and style of writing.
- Consumers will be encouraged to ask questions when language which is not patronising is used. Language that seems blaming or judgmental is best avoided. Examples include 'incompetent cervix' or 'this will be explained to you if appropriate'. Try to include 'kind' words such as 'the decision to have surgery is up to you'.
- Avoid using global imperatives, such as 'will', 'should', or 'must'. Preferred terms include 'You can obtain', or 'You may find it useful to'.
- Write in the second person (for example, 'you') rather than the third person, (for example, 'the patient').
- Consumer access is greatly enhanced if information is readily available in the consumer's language of choice. For medical terms where there is no equivalent, the translation needs to include English words in brackets.
- 'Back translating' will help to ensure the meaning is preserved. This refers to translating from the non-English version back into English.

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4.4.2 Presentation

General Presentation

- Though the length of a document will depend on the content and objectives, consumer health information tends to be most effective when it is short and informative. It is important to remember that a series of pamphlets may be better than a single product that tries to do too much.
- The use of colour is important in making consumer health information attractive and marketable. However, colour needs to be utilised sensitively with specific reference to the target group. For example, a menorrhagia brochure depicting a woman wearing a white dress is inappropriate.
- The quality and 'feel' of the paper used in pamphlets may influence the perceived quality and importance of the information. It may also be interpreted as an indication of the respect shown toward the consumer.

Diagrams, Graphs, Illustrations, Photographs and Pictures

If these are included they need to:

- Provide additional useful information to the text.
- Be clearly labelled.
- Be of adequate size in relation to the document and the level of complexity of the information being conveyed.
- Be culturally sensitive and appropriate, for example, some cultures are offended by the inclusion of drawings of unclad women.
- Show what a proposed treatment will involve.

Format

- Use a format that can convey information clearly. For example:
 - Question and answer format
 - Dot point formatting
 - Use of sections, columns and headings.
- Consider if all the information needs to be in one product or whether it is better separated into several products. In some situations consumers might find two types of written information useful, such as a short fact sheet and a more comprehensive pamphlet.

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Layout

- It is important for information under each heading to be relevant to that section.
- Headings and sections need to be well spaced. The spacing between sentences is also important in making the information readable.
- Use an easy-to-read font size. People are likely to appreciate larger size fonts.
- Pages should be numbered and the date of publication and author noted.
- If the product is lengthy, an index or table of contents will increase its usefulness.
- A summary of the main points at the end of the document, and/or tables comparing and contrasting treatment options or the benefits and risks of treatment, are useful.
- Information is best presented in a useful sequence, but this will not necessarily mean a chronological sequence. The most important information should be presented first with 'nice to know' information later.

4.4.3 Usefulness and Content

The content needs to reflect the aims of the written information. Therefore, not all of the following points may need to be included in every product.

- Where necessary, include a statement about the limitations of the information provided, indicating that it would not be possible to address all issues relevant to the topic.
- The information should reflect the diversity of the community rather than stereotyped images or ideas, such as assuming all women are mothers or that all obstetric cholecystectomy patients have supportive partners.
- The information needs to be gender neutral unless the condition is specific to a particular sex.

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Aims

A statement which clearly identifies what the product aims to achieve and the intended audience is a useful guide to the reader.

Aetiology

Consumers will be assisted by information about the causes of their condition, including:

- General information about the disease or condition, such as a clear definitions and a discussion of causes and the prognosis.
- Details of the risk factors associated with the disease or condition, accompanied by basic health information covering the normal ranges for bodily functions, such as blood pressure or blood loss.
- Relevant information about lifestyle factors, such as diet and exercise, as it relates to the condition.

Symptoms

Information about symptoms which consumers are likely to find helpful includes:

- The warning signs for onset of the condition.
- Information about the specific symptoms.
- Other conditions with similar symptoms.
- The causes and likelihood of associated pain.

Diagnosis

Diagnostic information which consumers may seek includes:

- All diagnostic tests and procedures available for the condition.
- Information about the relative benefits, the side-effects and risks associated with the tests, and the likelihood of these occurring.
- A description of the diagnostic process.

Treatment

Consumers will be interested in:

- Descriptions of both medical and complementary treatment options.
- Strategies for the management of symptoms.
- The interrelationship between treatment options and any other likely coexisting conditions.
- Balanced and unbiased presentation of treatment options.
- What to expect when having investigations or treatments, including after the event.

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Outcomes

Consumers will also want to know:

- The risks and benefits of treatment and procedures, including side-effects of medication.
- Any implications for pregnancy and breastfeeding (relevant to many women in the childbearing years).
- All aspects of recovery including recovery rates from surgery.
- Information on rehabilitation choices.
- The implications of treatment and the condition on social activities such as exercise, diet, sex and work, including the need for regular return visits or the potential for the treatment to render driving or heavy lifting inappropriate.
- Information about the prognosis and risks of recurrence.
- Both long- and short-term effects of the condition.

Psychosocial Impact

The psychosocial impact is important to consumers and information may be provided:

- About the social and emotional issues associated with the condition and their impact on the person, family and carer.
- About emotional states after treatment or associated with the condition, such as personal stories to help the consumer identify with the information.
- To the family to help explain what is happening, and how the partner, carer or family might help, including how they may all be feeling.

Prevention

Consumers may also be interested in information on how to prevent recurrence of their condition.

Other Resources

Consumers will be assisted by information about the availability of other useful resources outside the clinician–consumer consultation, such as:

- Contact details for relevant self-help groups.
- Other people able to provide further information or support. These contacts need to be accessible to the target audience (for example, rural consumers will need contacts in their area). They also need to be culturally and linguistically appropriate.
- References, date and authorship (see ‘Credibility’).

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4.4.4 Helping Decision Making

Written consumer information will be most effective in promoting consumer participation in treatment decisions if it addresses the following issues:

- What to do first, and an indication of whether the condition is an emergency.
- What questions to ask health practitioners about the treatments and their side effects.
- The qualifications and skills of the health practitioner and their level of expertise. This is often a difficult area for consumers to approach. It may be useful to provide some questions they might like to ask their doctor. For example, do they have specific qualifications in this area; how long have they been treating people with the condition; how many of these procedures do they perform each week/month/year; and what is their rate of readmission.
- Similar information or questions may also be suggested in relation to the health agency providing the overall care.
- How to go about obtaining a second opinion.
- Consent forms for tests and procedures and the reason for having them.
- Presenting available alternative diagnostic tests and treatments in an unbiased and non-judgmental way.
- Gaps in knowledge, uncertainties and controversies.
- Consumer rights.
- Access to support networks.

4.4.5 Credibility

To ensure the credibility and acceptance of consumer health information, it is necessary to include:

- The name and expertise of the author(s) (for example, qualifications and affiliations).
- The name of the publisher, publication date and copyright information.
- Current, accurate and consistent information.
- Language that is non-judgmental.
- Unbiased information.
- References to support information related to research and statistics.
- Information that is relevant and related to the consumer's experience.
- Disclosure of sponsors, for example if the product is funded by an organisation with a vested interest, such as a pharmaceutical company.
- Quality presentation of the information.
- References to other relevant literature.

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4.4.6 Evidence

General

- Consumer health information will be used if it is relevant to consumers and addresses the questions that matter to them. Use of both quantitative and qualitative information may be required to ensure greatest relevance.
- Information needs to be supported by referenced evidence.
- Searching for and critically appraising the clinical and other evidence is important. Members of the working group may not necessarily possess these skills. The local health service librarian can be of assistance and there are a number of publications that may provide a useful starting point⁽²⁾⁽³⁾.
- References to the evidence identified in written consumer information need to be provided.
- Information needs to be current.
- Be careful not to oversimplify the information. For the sake of clarity, it may be important to use the appropriate medical terminology, so long as it is properly explained.

Treatment Options

- Consumers need to understand the indications for a particular treatment and what would happen if they choose not to have treatment.
- All treatment options available for a condition need to be included. If this is not possible, the product should indicate where consumers may obtain such information.
- Provide a description of how the treatment works and if it is suitable for all patients.
- Information included needs to be balanced and unbiased.
- There needs to be the appropriate indication about the quality of the evidence and the level of evidence available to support each treatment option.

Treatment Outcomes

- Treatment outcomes need to be included.
- Treatment outcomes need to include both clinical outcomes as well as consumer-oriented outcomes. Examples of clinical outcomes include complications, perioperative mortality, health service readmission, and mortality. Consumer-oriented outcomes include general health and wellbeing, functional status and satisfaction with care.
- A balanced view of treatments will be most persuasive, including information about the benefits and risks as well as gaps and uncertainties in knowledge.
- The likelihood of successful/unsuccessful treatment outcomes need to be presented quantitatively. An easily understood way of presenting quantitative outcomes is by using probabilities (For example eight in 10 patients are cured of the condition) or the number needed to treat (for example, 18 patients need to be treated to avoid one death over a 12-month period).
- There needs to be a comparative analysis of treatment options, including the research evidence to support it.

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5. Evaluate and Modify the Draft Product

5.1 Evaluate the Draft Product

- Check the product for spelling mistakes and grammatical errors.
- Pilot the draft. Before the product is circulated it is useful to pilot it at a range of health practitioner and consumer forums. Piloting is a trial distribution in a defined small population and can provide an assessment of the effectiveness of the product.
- Get feedback. It may also be useful to evaluate the product by obtaining feedback on the draft from experts in the field (for example, university departments, leading clinicians at other health services); consumer organisations (such as self-help groups, advocacy organisations); and other health services providing similar services.

5.2 Modify Draft Product

- Make any improvements identified from the pilot/feedback prior to publication and dissemination.

6. Produce and Disseminate the Product

The working group will have planned for the dissemination of the product and must again identify to whom, when and how it will be disseminated. This involves publicising and marketing the consumer health information for use by all relevant and potential users. It is necessary to define and recommend processes that will encourage service providers to disseminate the products. The following points need to be considered at this stage:

- Check that the product meets the health service's approval protocols for publication.
- Consider the times at which consumers are likely to be most receptive to information.
- Remember that information is best provided as part of an ongoing professional and trusting relationship.
- Information is best retained if reinforced on several occasions.
- Information needs to be given in conjunction with discussion with members of the health care team.

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7. Maintaining and Evaluating the Information

Ongoing maintenance and evaluation processes of written consumer health information should take into account changing consumer needs and advances in research. The evaluation and maintenance processes may be the responsibility of the working group or delegated to a designated staff member.

To ensure ongoing maintenance and evaluation:

- Schedule dates for ongoing evaluation.
- Determine who will have responsibility for the maintenance and evaluation.
- Set a budget and identify sources of ongoing financial support for these activities.
- Set in place a process for monitoring the use and acceptance of the information by consumers and health practitioners. This can be accomplished through focus groups; surveys with practitioners and consumers; and also through feedback from the publisher as to the numbers of pamphlets or other written information products that have been distributed.

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8. Checklist for Assessing Written Consumer Health Information

This checklist is to assist health practitioners who are assessing the quality of written consumer health information. Sections A, B and C are relevant to all such information. Section D is relevant to products, such as pamphlets, that aim to help patients make decisions about their treatment and ongoing health care.

Section A Presentation

- Is the print legible? Yes Unsure No
- Is it appropriate for the intended consumer group? Yes Unsure No
- Is the information presented in sections? Yes Unsure No
- Do the sections have clear headings? Yes Unsure No
- Is there suitable spacing between the individual sentences? Yes Unsure No
- Is there suitable spacing between sections? Yes Unsure No
- Do the diagrams included provide useful information? Yes Unsure No
- Are the diagrams labelled? Yes Unsure No
- Are the diagrams of an adequate size? Yes Unsure No

Section B Language

- Is the language and tone used non-judgmental? Yes Unsure No
- Is the language used likely to be understood by the consumers who use it? Yes Unsure No
- Is the medical terminology, abbreviations, and jargon explained? Yes Unsure No
- Is it written in the second person (for example, 'you' instead of 'the patient')? Yes Unsure No
- Is the terminology used consistent? (that is, are the same words used to describe the same ideas, procedures or terms?) Yes Unsure No
- Does the product avoid the use of global imperatives? (for example, will, should, must) Yes Unsure No

Section C Content

- Is there evidence that consumers were involved in the production of the written consumer health information? Yes Unsure No
- Are the aims or objectives of the product clearly stated? Yes Unsure No
- Is the intended audience clearly stated in the product? Yes Unsure No

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- Does the product meet the specified aims? Yes Unsure No
- Is information presented in a sequence that is useful to consumers, that is, is the most useful information presented first? (This may not necessarily be a logical sequence) Yes Unsure No
- Is the information included in the product current? Yes Unsure No
- Is the evidence provided in the product referenced? Yes Unsure No
- Is the information presented in a balanced and non-biased way? Yes Unsure No
- Are there any omissions that the consumer needs to be aware of? Yes Unsure No
- Does the product provide information about areas of uncertainties in knowledge? Yes Unsure No
- Has information about further sources of support and help been included? Yes Unsure No
- Is the publisher included on the product? Yes Unsure No
- Is the date of publication included? Yes Unsure No
- Does the product contain the name or names of the author/s? Yes Unsure No
- Are the credentials of the authors included? Yes Unsure No
- Does the product encourage and support shared decision making or assist consumers to ask questions about their own treatment? Yes Unsure No

The following section is only relevant to written consumer health information that aims to help patients make decisions about their treatment.

Section D Treatment Options and Outcomes

- Are all the treatment options included? Yes Unsure No
- Is there a description of all the treatment options? Yes Unsure No
- Is there an indication of the quality and level of evidence to support these options? Yes Unsure No
- Are treatment outcomes provided, including information about the risks and benefits? Yes Unsure No
- Are the treatment outcomes quantified? Yes Unsure No
- Is there a comparative analysis of the treatment choices? Yes Unsure No
- Is there a balanced and unbiased description of the treatment options and outcomes? Yes Unsure No
- Is there mention of what might happen if the no treatment option is selected? Yes Unsure No
- Is information about the gaps and uncertainties in treatment provided? Yes Unsure No

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Notes

1 *A critical appraisal is the assessment of the methodological quality of a piece of research using an agreed upon set of criteria.*

2 Sackett, D.L. et al (1998) "*Evidence-based medicine: how to practice and teach EBM*"
Edinburgh: Churchill Livingstone.

3 Greenhalgh, T. (1997). "*How to read a paper; the basics of evidence based medicine*"
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