



Australian Government

National Health and Medical Research Council



MAKING DECISIONS ABOUT

TESTS AND TREATMENTS:

*PRINCIPLES FOR BETTER COMMUNICATION BETWEEN
HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS*





Australian Government

National Health and Medical Research Council

MAKING DECISIONS ABOUT TESTS AND TREATMENTS:
Principles for better communication between
healthcare consumers and healthcare professionals

ENDORSED 9TH DECEMBER 2005

© Commonwealth of Australia 2006

Paper-based publications

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced by any process without prior written permission from the Commonwealth available from the Attorney-General's Department. Requests and inquiries concerning reproduction and rights should be addressed to the Commonwealth Copyright Administration, Attorney General's Department, Robert Garran Offices, National Circuit, Canberra, ACT, 2600 or posted at: <http://www.ag.gov.au/cca>

ISBN Print: 186496314X

© Commonwealth of Australia 2006

Electronic documents

This work is copyright. You may download, display, print and reproduce this material in unaltered form only (retaining this notice) for your personal, non-commercial use or use within your organisation. Apart from any use as permitted under the Copyright Act 1968, all other rights are reserved. Requests for further authorisation should be directed to the Commonwealth Copyright Administration, Attorney General's Department, Robert Garran Offices, National Circuit, Canberra, ACT, 2600 or posted at: <http://www.ag.gov.au/cca>

ISBN Online: 1869463204

To obtain details regarding NHMRC publications contact:

Email: nhmrc.publications@nhmrc.gov.au
Phone: 13 000 NHMRC (13 000 64672 or 02 6217 9000)
Internet: <http://www.nhmrc.gov.au>

At the time of publication, the links to websites referred to in this document were correct. NHMRC acknowledge that, at times, organisations change internet addresses, or remove information from the internet.

Contents

INTRODUCTION	1
Scope of the toolkit	2
Structure of the toolkit	4
Process of development	7
PART 1 — PRINCIPLES	
PRINCIPLE 1: GOOD COMMUNICATION BETWEEN HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS HAS MANY BENEFITS	9
Background	9
What this means for healthcare consumers	10
What this means for healthcare professionals	10
Putting the principle into practice — tools for healthcare consumers	11
Examples	11
Putting the principle into practice — tools for healthcare professionals	14
Exercises for principle 1	17
Find out more	18
PRINCIPLE 2: HEALTHCARE CONSUMERS VARY IN HOW MUCH PARTICIPATION IN DECISION MAKING THEY DESIRE	25
Background	25
What this means for healthcare consumers	26
What this means for healthcare professionals	27
Examples	27
Putting the principle into practice — tools for healthcare consumers	29
Putting the principle into practice — tools for healthcare professionals	30
Exercises for principle 2	31
Find out more	33
PRINCIPLE 3: GOOD COMMUNICATION DEPENDS ON RECOGNISING AND MEETING THE NEEDS OF HEALTHCARE CONSUMERS	35
Background	35
What this means for healthcare consumers	36
What this means for healthcare professionals	37
Examples	37
Putting the principle into practice — tools for healthcare consumers	39
Putting the principle into practice — tools for healthcare professionals	41
Exercises for principle 3	45
Find out more	46

PRINCIPLE 4: PERCEPTIONS OF RISKS AND BENEFITS ARE COMPLEX, AND HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS MAY HAVE DIFFERENT PRIORITIES	53
Background	53
What this means for healthcare consumers	54
What this means for healthcare professionals	55
Examples	55
Putting the principle into practice — tools for healthcare consumers	56
Putting the principle into practice — tools for healthcare professionals	57
Exercises for principle 4	57
Find out more	59
PRINCIPLE 5: INFORMATION ON RISKS AND BENEFITS NEEDS TO BE COMPREHENSIVE AND ACCESSIBLE	61
Background	61
Decision aids	63
What this means for healthcare consumers	65
What this means for healthcare professionals	65
Examples	66
Putting the principle into practice — tools for healthcare consumers	67
Putting the principle into practice — tools for healthcare professionals	70
Exercises for principle 5	75
Find out more	76
PART 2 — CASE STUDIES	
CASE STUDY 1: DIAGNOSTIC INTERVENTION — PROSTATE SPECIFIC ANTIGEN (PSA) TESTING	83
Introduction	83
Current situation in communication about the PSA screening test	86
Applying the principles of good communication to decisions about PSA screening in men	88
Examples	93
Resources	95
References	98
CASE STUDY 2: PROCEDURAL INTERVENTION — CORONARY ANGIOPLASTY FOR HEART DISEASE	101
Introduction	101
Current situation in communication about coronary angioplasty	102
Applying the principles of good communication to decisions about coronary angioplasty	103
Example	105
Resources	107
References	108

CASE STUDY 3: MEDICATION INTERVENTION — GLUCOCORTICIDS	108
Introduction	108
Current situation in communication about glucocorticoid treatments	110
Applying the principles of good communication to decisions about treatment with glucocorticoids	111
Example	113
Resources	117
References	117
PART 3 — FURTHER INFORMATION	
RELEVANT ORGANISATIONS, WEBSITES AND RESOURCES	119
Australian organisations, websites and resources	119
International organisations, websites and resources	126
BIBLIOGRAPHY	129
APPENDIX 1: DEVELOPMENT PROCESS	143
APPENDIX 2: PUBLICATION, DISSEMINATION AND IMPLEMENTATION	153
APPENDIX 3: WORKING COMMITTEE	155
APPENDIX 4: INDIVIDUALS AND ORGANISATIONS SUBMITTING COMMENTS	157

Introduction

Healthcare often involves choosing between different options and making decisions — decisions for healthcare consumers (Should I have this test? Which treatment should I have?) and decisions for healthcare professionals (Should I request this test? What treatment should I recommend?). The decisions made depend on many factors, such as the consumer's values, concerns and expectations; the professional's knowledge, skills and attitudes; scientific evidence about what works and what doesn't work; the resources available in the healthcare system; how useful a test or treatment is; and the risks and benefits associated with a test or treatment.

In this complex environment, it is essential to have the best possible communication between consumers and professionals. In fact, we now know that good communication leads to better outcomes for everyone concerned. It benefits:

- healthcare consumers (the term used here to refer to patients, their carers and their families), because they are more satisfied with their care and are better empowered to proceed with an agreed course of action
- healthcare professionals (the term used here to refer to general practitioners, nurses, specialists, dieticians, physiotherapists, midwives, dentists, etc), because they are better able to build trusting relationships with consumers, and to find clinical practice more effective and satisfying.

Good communication can really make a difference in health; however, not all professionals have been formally trained in the skills needed to communicate well or to involve consumers in making decisions. Also, many consumers are not used to professionals asking their opinion or involving them in the decision-making process.

The National Health and Medical Research Council (NHMRC) has produced this toolkit to improve communication between consumers and professionals. Reflecting the nature of communication as a two-way process, the NHMRC has chosen to produce a single toolkit aimed both at those taking up and those delivering healthcare, rather than developing separate versions for consumers and professionals. The design of the document makes it clear which sections are aimed at both audiences, and which sections target consumers or professionals specifically.

SCOPE OF THE TOOLKIT

This toolkit aims to raise awareness of the importance of good communication and how communication can be improved. This means that both healthcare consumers and healthcare professionals can expand their communication skills and apply them more effectively to whatever medical situations they encounter. It extends and applies the information given in two earlier NHMRC publications:¹

- *Communicating with Patients: Advice for Medical Practitioners* (NHMRC 2004a)
- *General Guidelines for Medical Practitioners on Providing Information to Patients* (NHMRC 2004b).

The toolkit focuses on 'elective' medical situations; that is, non-emergency situations where there is a choice about whether or not to have a treatment or test, such as whether to have a screening test for a particular type of cancer. In elective situations, there is usually sufficient time for the decisions reached to fully reflect the different ways that people make decisions, based on their personal experiences and preferences. In such cases, it is vital that healthcare professionals explain and discuss options in a way that helps healthcare consumers make the best decisions. The same principles also apply to non-elective situations. Whenever possible, people seeking health advice should have opportunities to explain and discuss their values and preferences, so that the decisions reached can take these into account.

Although this toolkit may assist individual healthcare consumers and healthcare professionals, it is more likely to be useful as an educational resource, as described overleaf. In addition, the toolkit could be used to develop other resources for healthcare consumers and healthcare professionals. It is designed so that each of the principles could be studied separately, if required.

1 Available online at <http://www.nhmrc.gov.au>

Uses for the toolkit

This toolkit is an educational resource, for developing workshops and training modules for:

- healthcare consumer groups, carer organisations and support groups
- undergraduate and postgraduate healthcare professionals (nurses, doctors, dentists, physiotherapists, etc)
- overseas-trained healthcare professionals (for example, for use by certification boards)
- professional development (for example, for professional societies, group practices, area health services and Divisions of General Practice)
- senior staff within health services
- medical defence organisations
- students in years 11 and 12 (as part of a module about health)
- University of the Third Age (U3A).

Those who use this toolkit to develop training courses for healthcare professionals may wish to consider involving healthcare consumers as presenters at various points throughout the training, to help the professionals understand the issues for consumers in making decisions about tests and treatments. This model has been used successfully by the Australasian Society of Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) Medicine (ASHM) in training prescribers of particular drugs for HIV/AIDS.

This toolkit has a number of limitations in its scope. For example, it does not cover nonverbal communication, because the literature review on which it is based (discussed in Appendix 1) specifically excluded such communication. Also, it does not address the specific communication needs of particular subgroups of people, such as:

- infants, children and the elderly
- people from lower socioeconomic groups
- people from non-English speaking backgrounds and/or from different cultures
- Aboriginal and Torres Strait Islander people
- people with low health literacy
- people with mental health problems
- people with intellectual disabilities.

Furthermore, the toolkit does not address the complicated processes of communication where there are many different professionals involved, as in hospitals.

We hope that the generic principles outlined here can be applied and extended by readers to particular health issues and groups of people.

As part of the NHMRC process of publication review, this document will be reviewed five years from initial publication.

STRUCTURE OF THE TOOLKIT

Part 1 of the toolkit is built around five principles of effective communication in healthcare, based on the published literature. These are.

Principle 1 — Good communication between healthcare consumers and healthcare professionals has many benefits

There is evidence that good communication helps to build trusting relationships between consumers and professionals, leads to greater satisfaction on both sides; helps people to take more responsibility for their own health, and reduces medical errors and mishaps.

Principle 2 — Healthcare consumers vary in how much participation in decision making they desire

Some consumers prefer to make their own decisions about their healthcare, others prefer to give the responsibility to the professional, and many are somewhere between these two extremes. Also, a person's preferences for involvement may vary; for example, depending on how serious the medical situation is.

Principle 3 — Good communication depends on recognising and meeting the needs of healthcare consumers

Factors such as age, gender, health status, education and cultural background can affect communication between consumers and professionals. Recognising the impact of such factors helps to improve communication.

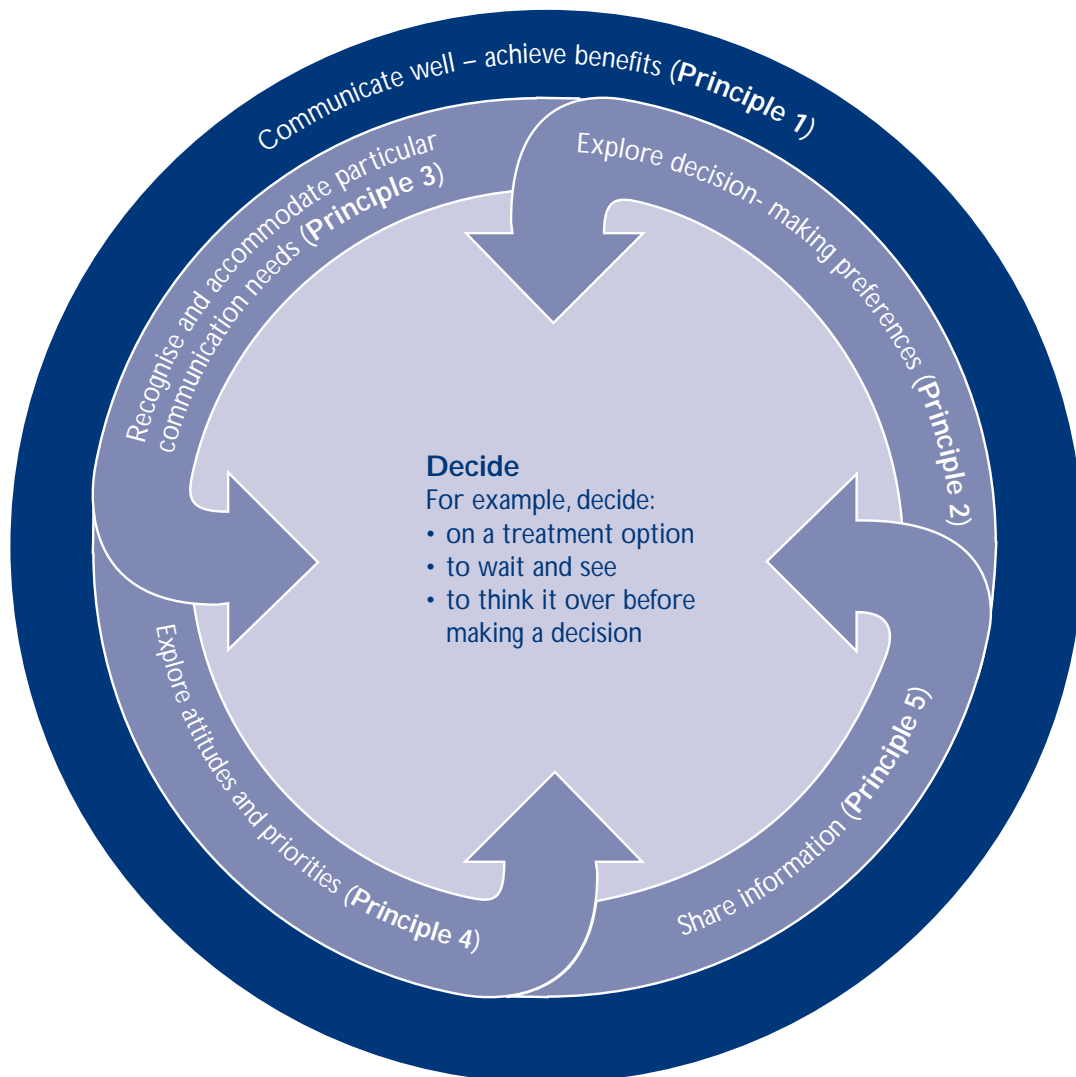
Principle 4 — Perceptions of risks and benefits are complex, and priorities may differ between healthcare consumers and healthcare professionals

Perceptions of risks and benefits are shaped by influences such as personal experiences, emotions and education, and thus differ from one person to another. Communicating these perceptions can help consumers and professionals to understand the other's perspective and arrive at decisions that meet the needs of the individual consumer.

Principle 5 — Information on risks and benefits needs to be comprehensive and accessible

Communicating risk in a way that is objective, useful and unbiased means taking into account factors such as emotions, language, images and perceptions; relevance and amount of information; uncertainty; and the effects of 'framing' information (for example, by portraying it in a positive or negative way).

The diagram shows how each of the five principles translates into an action. It also shows how the actions combine to help in reaching a decision, whether it be to opt for a particular test or treatment, wait and see, or seek further information.



Principle 1 — Good communication between healthcare consumers and healthcare professionals has many benefits

Principle 2 — Healthcare consumers vary in how much participation in decision making they desire

Principle 3 — Good communication depends on recognising and meeting the needs of healthcare consumers

Principle 4 — Perception of risks and benefits are complex, and priorities may differ between healthcare consumers and healthcare professionals

Principle 5 — Information on risks and benefits needs to be comprehensive and accessible

KEY

Healthcare consumers 

Healthcare professionals 

For each principle, the toolkit includes:

- background information
- an explanation of what the principle means for healthcare consumers and healthcare professionals
- examples of published studies that illustrate particular aspects of the principle
- tools and exercises (including case scenarios and questions) that could be adapted to suit particular circumstances, to help consumers and professionals to put the principle into practice
- sources of further information, including resources, organisations, websites and a list of the references on which the principle is based. (Many of the resources and websites were provided through the consultation process. Although they may be useful to readers, their quality has not been evaluated in developing this toolkit).

As explained above, the toolkit is designed more as a teaching or training tool than as a resource for individual consumers or professionals. Thus, the information given is not prescriptive, but is designed to stimulate debate and further learning.

Part 2 of the toolkit contains case studies covering three specific situations:

- a screening test — the prostate specific antigen (PSA) test
- a procedure — coronary angioplasty
- a medication — glucocorticoids.

Each case study gives some background information, and then illustrates how the principles outlined in Part 1 apply to that particular situation. The case studies also include hypothetical examples, given from healthcare consumer and healthcare professional perspectives. These are designed to illustrate particular issues; they could also be adapted, for example, for training purposes. Finally, each case study includes a list of publications used as the basis for that study.

Part 3 of the toolkit provides sources of further information. It includes:

- a set of resources — relevant publications, organisations and websites, (including those given in the individual principles)
- an alphabetical list of the key references (including those given in the individual principles and case studies).

PROCESS OF DEVELOPMENT

This toolkit is based on published information about achieving good communication between healthcare consumers and healthcare professionals. Many of the publications were identified through a literature review commissioned by the NHMRC in 2004 (Appendix 1 describes the process used to produce both the review and this toolkit; Appendix 2 describes the proposed strategy for dissemination and implementation). In particular, the literature review was used to develop the five principles described above, which form the basis of the toolkit.

The toolkit was developed from the evidence available. Each of the principles is derived from published studies, listed at the end of the principle (with systematic reviews identified as such). In addition, each principle is illustrated by a set of examples, which describe individual studies in sufficient detail to provide readers with an indication of the strength of the evidence and its applicability to the Australian situation.

Research studies can be classified as:

- quantitative studies, which are based on numbers, looking at measurable effects, using standardised data collection and statistical analysis
- qualitative studies, which are based on words, looking at behaviours and contexts, where the researcher is the primary ‘instrument’ of data collection and qualitative analysis.

Many of the research studies used as the basis for this toolkit were qualitative. This is not surprising, given that communication between healthcare consumers and healthcare professionals is essentially a form of social interaction between two people, and is best handled by qualitative methodologies. However, the criteria developed by the NHMRC for assessing the level and quality of research evidence mainly apply to quantitative rather than qualitative studies, and therefore could not be applied here in the way that they have been in publications such as clinical practice guidelines. Other considerations relating to the evidence base included the fact that there are substantial gaps in the research literature (highlighted where appropriate in the toolkit), and also that relatively few of the published studies on this topic are from Australia.

This toolkit was enriched by the process of public consultation. Comments were received from individuals, and from consumer and professional groups. These helped to improve the scenarios, make the document more appropriate for its purpose and expand the lists of resources referred to in the toolkit.

Principle 1:

Good communication between healthcare consumers and healthcare professionals has many benefits

This principle and the information supporting it are based on the references listed at the end of this section

BACKGROUND

This principle and the information supporting it are based on the references listed at the end of this section

Good communication between healthcare consumers and healthcare professionals has many benefits. It builds trust, makes clinical practice more effective, and reduces the likelihood of errors and mishaps. It also means that consumers are more likely to:

- participate fully in their own healthcare
- use their healthcare professional as a reliable source of information
- follow an agreed plan for treatment or management
- keep medical appointments
- remember medical information
- take up healthy behaviours, such as doing more exercise, stopping smoking or improving their diet
- feel that they have greater control over their health decisions
- have more realistic expectations
- be more satisfied with their healthcare
- have greater confidence in themselves and their ability to cope with and handle their illness (a concept described as 'self-efficacy', described below).

Self-efficacy²

Self-efficacy is the measurable capacity to organise and carry out a course of action needed to achieve a goal. Being diagnosed with an illness can affect a person's confidence in their ability to take care of themselves. Some people even feel as though their bodies have betrayed them. Such feelings tend to decrease a person's self-efficacy. Therefore, one of the aims of good communication between healthcare consumers and healthcare professionals should be to improve self-efficacy, giving consumers confidence in their own abilities. This means going beyond simply giving information, to explore what tools and skills consumers already have, or need to develop, to help them to achieve their health goals.

A recent study in Australia illustrated how education and self-management programs for people with arthritis could increase self-efficacy, and improve healthcare and outcomes (Osborne et al 2004).

² The term 'self-efficacy' was first coined by Albert Bandura. A list of publications on this topic can be found at <http://www.emory.edu/EDUCATION/mfp/BanduraPubs.html>

What this means for healthcare consumers

Playing an active part in your own healthcare can have many benefits. Good communication between you and your healthcare professional depends on both of you recognising that the other is an expert. The professional has medical knowledge, but you know more than anyone else about how your health condition affects you. You also know most about your beliefs, concerns, values and preferences.

Good communication can help to ensure that you are:

- informed about your condition and your treatment options
- given information in language that you can understand
- involved, to the extent you feel comfortable with, in making decisions about your treatment.

Communication is a two-way street, and you have a crucial role to play, for example in telling the professional about your condition and how you feel about it, as well as your views on the options for diagnosis and treatment. You can do this by asking questions, expressing your opinions and providing information about what is important to you. The 'tools for healthcare consumers' section of this principle provides some ideas on how you might do this.

What this means for healthcare professionals

Communicating well with healthcare consumers brings many benefits both for healthcare consumers and for healthcare professionals. Successful communication depends on both parties recognising and respecting the contribution that the other brings to the discussion — you bring professional healthcare expertise and experience, whereas the consumer brings expertise in their personal experience of the medical condition, and in their values and preferences.

Having a better understanding of the person may make it easier for you to help them make decisions they feel comfortable with. Thus, it can be useful to encourage consumers to talk about themselves and their beliefs, priorities and concerns.

Increasing the participation of consumers does not necessarily mean longer consultations. It can make consultations more time efficient, because sharing information about options and getting feedback can help you provide information to consumers in a suitable form and style and with content that is relevant to them. This is an important consideration, given that time is a major issue for many healthcare professionals. For example, a recent review of GPs found that what they wished for most in their clinical practice was more time to spend with their patients (Chew 2005), and a recently published self-care guidebook for medical practitioners (also relevant for other health professionals) emphasises the need for professionals to make time for themselves as well as their patients (Clode and Boldero 2005).

The 'tools for healthcare professionals' section of this principle has some ideas for strategies you could use to improve communication with consumers, and to encourage them to share information.

Putting the principle into practice — tools for healthcare consumers

This section provides ideas about what you might like to get out of a visit to your healthcare professional, and questions you might ask during your consultation. It also provides information about various resources aimed at helping consumers to become more actively involved in their healthcare.

EXAMPLES

The following studies and stories illustrate some aspects of the principle that good communication has many benefits.

Studies

Providing information improves health outcomes

A review of the literature over the past 50 years found a number of studies indicating that giving healthcare consumers information (for example, a basic patient information sheet before surgery) has benefits that include:

- reducing the number of complications and the length of time people stay in hospital
- reducing the need for pain relief after surgery
- increasing people's feelings of satisfaction about their healthcare.

Giving consumers pre-operative information can save money in the long term and lead to better health outcomes.

Source: Garretson 2004.

Training benefits both experienced and new healthcare professionals

A study of 79 Chinese general practitioners (GPs) in Hong Kong found that communication skills could be improved by training. The GPs were trained over 10 months, through lectures, role plays and self-analysis of videotaped interviews. After the training, it was found through videos and performance checklists that the GPs had markedly improved in their interactions with healthcare consumers. GPs with 20 or more years experience improved as much as their younger counterparts.

Source: Chan et al 2003a.

Healthcare consumers' participation in medical communication can be improved by simple measures

A systematic review looked at 25 studies designed to increase healthcare consumers' participation in clinical consultations, mostly in outpatient or primary care settings. Generally, the studies showed that certain interventions directed at consumers increased their participation, without necessarily increasing the length of the consultation. Examples of such interactions included instructing consumers to ask questions, or giving them a question prompt sheet. Encouraging participation gave consumers a greater sense of control and made it more likely that they would prefer an active role in future consultations.

Source: Harrington et al 2004.

WHAT WOULD YOU LIKE TO ACHIEVE?

In thinking about what you can do to communicate better with your healthcare professional, it may be helpful to start by thinking about how your condition affects you, how much it bothers you and what you would like to do about it. Considering these questions can help you to work out what you want from a consultation. For example, think about the situation of a woman who is having hot flushes due to the menopause, particularly at night, which stop her sleeping well. She is going to see a general practitioner (GP) about whether to take hormone replacement therapy (HRT) to reduce the hot flushes. What might her goals be? Perhaps to obtain sufficient information about the pros and cons of the treatment, so that she can talk to family or friends, and then decide whether HRT is right for her.

Similarly, think about the situation of a young man who has a rash that he thinks might be due to a sexually transmitted disease (STD) contracted from his girlfriend. The young man is visiting a sexual health clinic about the problem. What might his goals be? As well as determining the cause of his rash and obtaining appropriate treatment, he may (if he does have an STD) wish to get advice on how to raise the issue with his girlfriend.

USEFUL QUESTIONS

You may find it helpful to prepare a list of questions before you talk to your professional. For example, you might ask things like:

- How serious is my condition?
- How much will it affect my day-to-day life?
- What are my options?
- What exactly does this procedure, test, treatment or surgery involve?
- What are the side effects of each of the options?
- How much will each test or treatment cost?
- What are the potential risks and benefits of the test, treatment or surgery?

You can use this sample as a guide to help you choose the questions that are important for you. Your questions do not have to be restricted to your particular health issue; they can cover other things that may be relevant for you. For example, if you are seeing a physiotherapist who is recommending a certain therapy for a problem with your wrist, you might like to know how the

proposed treatment will affect your ability to drive. The Health Consumers' Council of Western Australia has prepared a sample questionnaire *Questions to Ask Your Doctor*, which lists these and other questions that you might like to ask.³

RESOURCES FOR BECOMING MORE ACTIVELY INVOLVED IN YOUR HEALTHCARE

10 Tips for Safer Health Care⁴

10 Tips for Safer Health Care is a booklet that aims to help people be more actively involved in their own healthcare; it is produced in 15 languages (ACSQHC 2003).

The booklet describes why healthcare safety is important, as well as how things can go wrong. For example, it discusses what can happen when people misunderstand information, such as when healthcare professionals misread prescriptions and give people the wrong medication, or when they mishear something that a consumer says. The booklet gives the following tips on how you can work with your healthcare professionals to prevent these types of problems:

- Be actively involved in your own healthcare.
- Speak up if you have any questions or concerns.
- Learn more about your condition and treatments.
- Keep a list of all the medicines you are taking.
- Make sure you understand the medicines you are taking.
- Get the results of any test or procedure.
- Talk about your options if you need to go into hospital.
- Make sure you understand what will happen if you need surgery or a procedure.
- Make sure you, your doctor and your surgeon all agree on exactly what will be done.
- Before you leave hospital, ask healthcare professionals to explain the treatment plan you will use at home.

The booklet also provides details of who you can contact if you are worried about your healthcare or if you would like more information. The *Find out more* section of this principle gives details of where you can obtain this booklet, and the other resources mentioned in this section.

3 Available online at http://www.hcc-wa.global.net.au/pages/questions_doc.html

4 Available at <http://www.safetyandquality.org/index.cfm?page=publications#10tips>

Smart Health Choices⁵

The book *Smart Health Choices: How to Make Informed Health Decisions* offers simple tools you can use to assess the value of health advice and work out how to use that advice. The authors suggest that ‘this knowledge could mean the difference between choosing the most effective treatment or choosing one which may be useless or even life threatening’.

The Resourceful Patient⁶

The Resourceful Patient is a web-based book and toolkit for those wishing to address current problems of healthcare. Particularly relevant here is Section 3 of the book, which is titled *Skills and Resources for Resourceful Patients*. It covers skills for appraising information, consulting and making decisions, and also includes information on coaching, confidence and authority.

HEALTHCARE CONSUMER-ORIENTED INFORMATION ON THE INTERNET

The *Find out more* section of this principle lists some of the many websites, both Australian and international, that provide information for consumers.

EXERCISES FOR HEALTHCARE CONSUMERS

At the end of this section, there are scenarios and questions designed to help healthcare consumers and healthcare professionals put into practice the tools and information given in this principle.

Putting the principle into practice — tools for healthcare professionals

This section provides ideas on:

- thinking about what you might like to achieve during a consultation
- behaviours that have been found to improve healthcare consumer satisfaction
- training in communication skills.

5 Irwig et al 1999

6 Available from eRosetta, 59 Lakeside Oxford OX2 8JQ, UK or online at <http://www.resourcefulpatient.org/index.htm>

WHAT WOULD YOU LIKE TO ACHIEVE?

In thinking about what you can do to communicate better with consumers, it may be helpful to think about your goal for the consultation. For example, put yourself in the place of a GP being consulted by a woman who would like to know whether or not to take hormone replacement therapy (HRT) for hot flushes. What would your initial goal be? Perhaps to discuss the pros and cons of HRT, and provide the woman with information to take away, so that she can go home and think about her options, and discuss them with family or friends before coming back to make a decision.

HELPFUL BEHAVIOURS

Certain types of behaviour on the part of professionals can improve consumer satisfaction with their healthcare. A review of scientific literature over 25 years identified a number of behaviours that improve consumer satisfaction. These can be summarised as follows:

- Set the right tone and put the person at ease.
- Be a good listener.
- Provide information.
- Develop a partnership.

Some of the specific behaviours identified in the review that relate to each of these main points are included on the following page.

If you would like to assess your own interactions with consumers, a good place to start could be to ask yourself: 'Which of these behaviours am I managing well?' and 'Are there areas that I could improve on?' You could then decide to focus on improving one of the areas in which you feel you could do better.

TRAINING

Many healthcare professionals have not been formally trained in the understandings and techniques needed for successful communication with consumers. General training in communication does not necessarily cover the specific skills and strategies needed to involve consumers in decision making.

If you would like to undertake training in communication, contact your professional organisation to find out whether they offer any relevant courses or know of other organisations that might do so. Even experienced professionals can benefit from training, as shown by the study by Chan et al (2003a) (see *Examples* section of this principle).

Behaviours found to increase healthcare consumers' feelings of satisfaction

Set the right tone, put the person at ease

- Be friendly, courteous, congenial and empathic.
- Be positive about the person and their actions.

Be a good listener

- Take the consumer's history.
- Encourage and listen to questions.
- Be receptive to questions and statements.
- Ask appropriate open questions (as well as closed questions) about psychosocial issues, such as problems of daily living, social relations, feelings and emotions.

Provide information

- Provide health education.
- Share medical information.
- Discuss treatment effects.
- Summarise, in language the consumer can understand.
- Clarify statements.

Develop a partnership

- Give reassurance.
- Offer support.
- Show that you appreciate the consumer's situation.

These behaviours were identified in a systematic review of the scientific literature from 1975 to 2000 that covered interactions between primary care physicians and patients. Studies were only included if the interaction was evaluated by a neutral observer (who coded the interview based on observation, audiotape or videotape); 22 studies met the criteria and were included in the review.

Source: Beck et al 2002.

EXERCISES FOR HEALTHCARE PROFESSIONALS

The following scenarios and questions are designed to help healthcare professionals and healthcare consumers put into practice the tools and information given in this principle.

Exercises for principle 1

Imagine you are in the position of the healthcare consumer or healthcare professional in the following scenarios, and think about how you might answer the questions below.

Scenario 1

George is a 60-year-old man who is somewhat overweight. Recently, he has been bothered by a pain in his right knee, which he thinks could be arthritis. He visits his GP to find out what he can do to relieve the pain, and stop it getting worse. In particular, he is worried about putting on more weight, because the pain is stopping him from taking his daily walk. A friend has told him that she takes a medicine called glucosamine, which is available over the counter and has really helped her joint pains. George does not like taking medications on a regular basis, but now he is wondering whether he should be taking glucosamine or some other drugs. He knows that some people take anti-inflammatory medications for arthritis, but has heard that they can have some nasty side effects.

Scenario 2

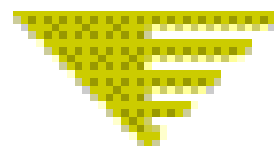
Katrina is a 40-year-old woman who visits her GP about a lump that has recently developed in her neck. After discussion, examination and an ultrasound test, the GP recommends a biopsy to rule out the slight possibility that the lump is a cancer. This would involve a fine needle being inserted into the lump so that some tissue can be taken for testing. Katrina's father died of cancer soon after having a biopsy of his liver. She thinks the events may have been related, and because of this she is reluctant to have the biopsy.



What do I really want to get from this consultation?

What matters to me, and how could I let the GP know this?

What questions do I have for the GP about my condition or the suggested treatment?



How could I help this person to feel at ease?

How could I find out what they want from this consultation?

How could I help them to voice their concerns about their condition or the treatment I'm suggesting?

Find out more

CASE STUDIES

The three case studies in Part 2 of this toolkit illustrate the benefits of good communication, and some of the problems caused by poor communication.

RESOURCES

10 Tips for Safer Health Care

Booklet available from the Australian Commission on Safety and Quality in Health Care, published in 15 languages.

Address: MDP 46, GPO Box 9848, Canberra, ACT 2601

Phone: 02 6289 4244

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

Health Matters consumer guides

These guides, produced by the Australian Broadcasting Corporation, are designed to help healthcare consumers make sense of medical research and get the most out of their professional care.

Address: 4th Floor, ABC Ultimo Centre, GPO Box 9994, Sydney, NSW 2001

Phone: 139994

Website: <http://www.abc.net.au/health/cguides/default.htm>

(including *Cancer Screening: Is it Worth it?*

<http://www.abc.net.au/health/thepulse/s1438910.htm>

and *Cancer Screening — Benefits and Harms*

<http://www.abc.net.au/rn/talks/8.30/helthrpt/stories/s1440410.htm>)

Medimate

This consumer brochure is produced by the National Prescribing Service. Its aim is to help healthcare consumers to find, understand and use information about medicines. It encourages healthcare consumers to do this in partnership with their healthcare professionals. Medimate covers prescription medicines, over-the-counter medicines and natural and herbal medicines. It is available in several other languages — Chinese, Greek, Italian and Vietnamese.

Address: PO Box 1147, Strawberry Hills NSW 2012

Phone: 02 8217 8700

Website: http://www.nps.org.au/resources/content/medimate_brochure.pdf

Questions to Ask Your Doctor

Sample questionnaire prepared by the Health Consumers' Council of Western Australia.

Address: GPO Box C134, Perth, WA 6839

Phone: 08 9221 3422; Freecall: 1800 620 780

Website: <http://www.hcc-wa.global.net.au>

Questionnaire: http://www.hcc-wa.global.net.au/pages/questions_doc.html

Smart Health Choices: How to Make Informed Health Decisions

Book by J Irwig, L Irwig and M Sweet (1999), Allen & Unwin, NSW, Australia.

The Resourceful Patient

Web-based book and toolkit, available from eRosetta, 59 Lakeside, Oxford OX2 8JQ, United Kingdom, or online at <http://www.resourcefulpatient.org/index.htm>.

RELEVANT ORGANISATIONS AND WEBSITES

Australian Competition and Consumer Commission

The Australian Competition and Consumer Commission (ACCC) has developed an information kit for healthcare professionals title *Straight Talking with your Patients*, which includes suggestions on providing information and disclosure of fees to healthcare consumers.

Website: <http://www.accc.gov.au>

Australian Commission on Safety and Quality in Health Care

Resources available from the commission's website include *10 Tips for Safer Health Care* and *National Patient Safety Education Framework Bibliography*.

Address: MDP 46, GPO Box 9848, Canberra, ACT 2601

Phone: 02 6289 4244

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

Cochrane Collaboration and Cochrane Consumer Network

The Cochrane Collaboration is an international not-for-profit organisation, providing up-to-date information about the effects of healthcare.

Website: <http://www.cochrane.org/index0.htm>

The Cochrane Consumer Network aims to provide consumer input into developing Cochrane systematic reviews of best evidence in healthcare and in using this evidence.

Website: <http://www.cochrane.org/consumers/homepage.htm>

Consumers' Health Forum of Australia

The forum is a national organisation providing a voice for all healthcare consumers. Its members include consumer organisations that represent a broad range of consumers such as illness groups, disability groups and specific population groups (youth, older people, women, etc).

Address: PO Box 3099, Manuka, ACT 2603

Phone: (02) 6273 5444

Website: <http://www.chf.org.au>

Health *Insite*

An initiative of the Australian Government, this website provides a wide range of up-to-date and quality assessed information on important health topics such as diabetes, cancer, mental health and asthma.

Website: <http://www.healthinsite.gov.au>

Health Consumers' Council (Western Australia)

The council is an independent community-based organisation, representing the consumer's 'voice' in health policy, planning, research and service delivery.

Address: GPO Box C134, Perth, WA 6839

Phone: 08 9221 3422; Freecall: 1800 620 780

Website: <http://www.hcc-wa.global.net.au>

Human Behaviour and Health Research Unit (Flinders University, South Australia)

The unit is a centre for research, evaluation and development of chronic condition management. This includes coordinated care, care planning, behavioural change and self-management, and the education and training of healthcare professionals and healthcare consumers.

Address: GPO PO Box 2100, Adelaide, SA 5001

Phone: 08 8404 2323

Website: <http://som.flinders.edu.au/FUSA/CCTU/home.html>

Information on self-efficacy

A list of resources about self-efficacy, produced by Emory University, United States. Includes information on what self-efficacy is and how it differs from confidence.

Website: <http://www.emory.edu/EDUCATION/mfp/self-efficacy.html>

Informedhealthonline

This site is produced by the Health Research and Education Foundation Ltd, a health promotion charity based in Melbourne. The foundation aims to provide information and resource tools that enable people to keep up to date with reliable, evidence-based information. It promotes research literacy, and individual and community use of high-quality research.

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

STATE AND TERRITORY HEALTH DEPARTMENTS

Australian Capital Territory: ACT Health

Address: GPO Box 825, Canberra, ACT 2601

Phone: 13 22 81

Website: <http://www.health.act.gov.au/c/health>

New South Wales: NSW Health

Address: Locked Mail Bag 961, North Sydney, NSW 2059

Phone: 02 9391 9000

Website: <http://www.health.nsw.gov.au>

(includes *Living* website for consumers —
<http://www.health.nsw.gov.au/living/index.html>)

Northern Territory: Department of Health and Community Services

Address: PO Box 40596, Casuarina, NT 0811

Phone: 08 8999 2400

Website: <http://www.nt.gov.au/health/index.shtml>

Queensland: Queensland Health

Address: GPO Box 48, Brisbane, Queensland 4001

Phone: 07 3234 0111

Website: <http://www.health.qld.gov.au>

South Australia: South Australia Department of Health

Address: PO Box 287, Rundle Mall, Adelaide SA 5001

Phone: 08 8226-6000

Website: <http://www.health.sa.gov.au>

(includes *HealthySA* website for consumers —
<http://www.healthysa.sa.gov.au>)

Tasmania: Department of Health and Human Services

Address: 34 Davey Street, Hobart, TAS 7000

Phone: 03 6233 3185

Website: <http://www.dhhs.tas.gov.au>

(includes *Healthy Living* website for consumers —
<http://www.dhhs.tas.gov.au/healthyliving>)

Victoria: Department of Human Services

Address: GPO Box 4057, Melbourne, Vic 3001

Phone: 03 9616 7777

Website: <http://hnp.dhs.vic.gov.au>

(includes *Better Health* website for consumers —
<http://www.betterhealth.vic.gov.au>)

Western Australia: Health Department of Western Australia

Address: PO Box 8172, Perth Business Centre, Perth, WA 6849

Phone: 08 9222 4222

Website: <http://www.health.wa.gov.au>

(includes *HealthWay* website for consumers —

<http://www1.healthway.wa.gov.au>)

BIBLIOGRAPHY

An asterisk * after a reference indicates that the study was a systematic review.

Abbott SA (1998). The benefits of patient education.

Gastroenterology Nursing 21:207–209.

Beck RS, Daughtridge R and Sloane PD (2002). Physician–patient communication in the primary care office: a systematic review.

Journal of the American Board of Family Practice 15:25–38.*

Chan EC, Haynes MC, O'Donnell FT, Bachino C and Vernon SW (2003a). Cultural sensitivity and informed decision making about prostate cancer screening. *Journal of Community Health* 28:393–405.

Chew M (2005). What GPs want: time and time again. *Medical Journal of Australia* 183:58–59. http://www.mja.com.au/public/issues/183_02_180705/che10466_fm.html

Clode D and Boldero J (2005). *Keeping the Doctor Alive: A Self-Care Guidebook for Medical Practitioners*, Royal Australian College of General Practitioners: South Melbourne.

Cowap S (2005). Time trials. *Medical Journal of Australia* 183:72. http://www.mja.com.au/public/issues/183_02_180705/cow10451_fm.html

Department of Health (UK) (2001). *The Expert Patient: A New Approach to Chronic Disease for the 21st Century*. London, Department of Health.

Eggly S (2002). Physician–patient co-construction of illness narratives in the medical interview. *Health Communication* 14:339–360.

Elwyn G and Gwyn R (1999). Narrative based medicine: Stories we hear and stories we tell: analysing talk in clinical practice. *British Medical Journal* 318:186–188.

Garretson S (2004). Benefits of pre-operative information programs. *Nursing Standard* 18:33–37.

- Grey MJA (2002). *The Resourceful Patient*. Rosetta Press, UK. <http://www.resourcefulpatient.org/index.htm>
- Harrington J, Nobel LM and Newman SP (2004). Improving patients' communication with doctors: a systematic review of intervention studies. *Patient Education and Counseling* 52:7–16.*
- Irwig J, Irwig L and Sweet M (1999). *Smart Health Choices: How to Make Informed Health Decisions*, Allen & Unwin, NSW, Australia.
- NHMRC (National Health and Medical Research Council) (2004a). *Communicating with Patients: Advice for Medical Practitioners*. Commonwealth of Australia.
- NHMRC (2004b). *General Guidelines for Medical Practitioners on Providing Information to Patients*. Commonwealth of Australia.
- NHS (National Health Service) Centre for Reviews and Dissemination (2000). *Effective Health Care: Informing, Communicating and Sharing Decisions with People who have Cancer*. Royal Society of Medicine Press.
- Osborne RH, Spinks JM and Wicks IP (2004). Patient education and self-management programs in arthritis. *Medical Journal of Australia* 180:S23–S26. http://www.mja.com.au/public/issues/180_05_010304/osb10565_fm.html
- Roberts C (2004). 'Only connect': the centrality of doctor–patient relationships in primary care. *Family Practice* 21:232–233.
- Rowland-Morin PA and Carroll JG (1990). Verbal communication skills and patient satisfaction. A study of doctor–patient interviews. *Evaluation and the Health Professions* 13:168–185.
- Suarez-Almazor ME (2004). Patient physician communication. *Current Opinion in Rheumatology* 16:91–95.
- Teutsch C (2003). Patient–doctor communication. *The Medical Clinics of North America* 87:1115–1145.

Principle 2:

Healthcare consumers vary in how much participation in decision making they desire

This principle and the information supporting it are based on the references listed at the end of this section

BACKGROUND

Many studies have found that healthcare consumers would like more information relevant to their own situation and more opportunities to participate in decision making than they are currently getting.

In the past, healthcare professionals have tended to make decisions about the selection of tests or treatments, without necessarily involving healthcare consumers to any great degree. Today, this situation is changing because — as in other areas of life — healthcare consumers often expect greater involvement in decision making. A summary of the different approaches to decision making follows.

Different approaches to decision making

- **Traditional or paternalistic approach** — In this approach, decision making is left mainly to healthcare professionals, who generally make the decisions and recommend a particular course of action, often without involving healthcare consumers to any great extent in the decisions.
- **Informed decision making** — In this approach, consumers make decisions based to some extent on information provided by professionals. The flow of information is mostly one way, from professionals to consumers.
- **Partnership approach or shared decision making** — In this approach, consumers and professionals share relevant information (for example, about risks, benefits, consumer's characteristics and values), and agree on decisions.

Despite moves towards more informed and partnership approaches, the reality is likely to be a mix of these different types of decision making, depending on the individuals involved and the circumstances.

People vary in how much they wish to be involved in making decisions about their health. Some consumers are comfortable making their own decisions, whereas others prefer to give the professional most of the responsibility for decision making. Many people are comfortable with a situation somewhere between these two extremes, sharing decisions with their professionals to a greater or lesser extent. Figure 2.1 illustrates these different preferences.

Figure 2.1 Variation in preferences for involvement in decision making



Preferences for being involved in decision making are not fixed — they change depending on factors such as the seriousness and urgency of the decision, the person’s state of health at the time and how well informed they feel. For example, someone with a serious illness that requires an urgent decision may prefer their healthcare professionals to make decisions about options for tests and treatment. In a less serious or urgent situation, that same person might feel comfortable making decisions themselves, often with their professionals’ help in finding and discussing additional information. Similarly, someone with a long-term illness, such as diabetes, may feel confident making their own decisions because they get to know a great deal about their condition, the options for treatment or management, and what works and doesn’t work for them. However, in certain situations, that person may prefer their professional to be more involved; for example, if the consumer has to decide whether to take antibiotics for a serious infection that is making them feel too unwell to take in new information.

Whatever their preferences for being involved in decisions, most consumers would like to feel informed: ‘Most patients want to see the road map, including alternative routes, even if they don’t want to take over the wheel’.⁷

What this means for healthcare consumers

How much you wish to make decisions about your healthcare yourself and how much you wish to give this responsibility to your healthcare professional is your choice. Your preferences for involvement may vary, depending on things such as how serious the decision is, how urgent it is, your own feelings (based on your knowledge and experience) and the information you have.

Whether or not you choose to be involved in making decisions, you should still expect to receive care and support from your health professional, and to receive sufficient information to understand your illness and your options for treatment, to the extent that you wish.

continued »

⁷ Kravitz and Melnikow 2001

continued »

The idea of shared decision making in healthcare may be something that is new both to you and to your professional. Neither of you may feel comfortable with it at first.

The *Tools for healthcare consumers* section that follows has ideas on how you can be more involved in decision making, if you wish.

What this means for healthcare professionals

Although factors such as gender, age, education and culture affect healthcare consumers' desire to be actively involved in decision making, there is so much variation between individuals that it is best not to make assumptions about people's preferences for involvement. Whether or not consumers want to make decisions, most hope that you will provide them with relevant information; they also want to be listened to.

Think about your own consultations. Do you take the time to identify the wishes of the consumer? Do you help them to feel comfortable expressing their preferences for involvement in decision making? Generally, people appreciate being given the chance to give more information about themselves, their values and their preferences.

Whether or not consumers want to make their own decisions, your expertise is still important to the discussion and to helping the person to make their decisions. For example, you might help the consumer to find additional information and discuss options until they are comfortable with the decision they make. Your role could perhaps be described as being a 'navigator', guiding the consumer, rather than a 'pilot', plotting the path they should take.

If you feel that you could do more to encourage consumers to participate in making decisions about their health, the *Tools for healthcare professionals* section of this principle has ideas on how you can do this.

EXAMPLES

The following studies and stories illustrate some aspects of the principle that healthcare consumers vary in how much involvement in decision making they desire.

Studies

Preferences are affected by a person's medical condition

A study in Canada compared preferences for decision making in 436 newly diagnosed cancer patients and 482 members of the general public, and found a big difference between the two groups. Most people (64%) in the general public group thought they would want to select their own treatment if they had cancer. However, among the people newly diagnosed with cancer, only 12% preferred to be actively involved in decision making and 59% wanted their health professional to select the treatment

continued »

continued »

for them. In both groups of people surveyed, those who were younger and those who had a higher level of education were more likely to prefer control over decisions.

Source: Degner and Sloan 1992.

Many healthcare consumers would like more information

A study in the United States asked 200 people with hypertension and 50 healthcare professionals about healthcare consumers' desire for information and participation in decision making. The researchers found that professionals tended to underestimate consumers' desire for information, with about 40% of consumers wanting more information than they were given. On the other hand, the professionals tended to overestimate the consumers' desire to make decisions; for example, they believed that about three-quarters of consumers preferred to participate in decision making, when only about half the consumers actually wished to do so.

Source: Strull et al 1984.

Shared decision making new to GP registrars

A study of 39 GP registrars in South Wales (UK) used focus groups and simulated consultations to develop a model for shared decision making. All the registrars found the concept of shared decision making novel, and felt that they had not been trained to successfully involve healthcare consumers in decisions. However, they were positive about the techniques explored for involving consumers in decisions, and said that shared decision making increased their sense of confidence. Some registrars were concerned about potential anxiety in consumers given too much information or responsibility for making decisions.

Source: Elwyn et al 1999.

Barriers to consumer participation

An Australian study used focus group interviews and observation to investigate the approaches nurses used to support consumers' participation in healthcare delivery. The study looked at 20 nurses, in three focus groups, in an acute care setting. The researchers found a sharp contrast between the ideas the nurses expressed (where they had adopted the rhetoric of consumer participation) and their actions in practice. Division of nursing labour, limited communication between nurses and consumers, and environmental constraints were factors limiting consumer involvement. Suggestions for improving consumer participation included innovative strategies for improving staff development, and management-led organisational change. The authors also noted that change depended on healthcare management beginning to understand and resolve communication barriers.

Source: Wellard et al 2003.

Putting the principle into practice — tools for healthcare consumers

This section provides ideas on how you can work out what your preferences are for being involved in decision making, and how you can let your healthcare professional know about those preferences.

THINK ABOUT YOUR PREFERENCES

Think about the last few times you visited your doctor, nurse practitioner, dentist, physiotherapist or other healthcare professional.

- What decisions were made about your treatment or the management of your health?
- Who made those decisions — was it you or the professional? Alternatively, did the two of you discuss various options and come to a decision together, after you had considered additional information?
- Did the decision making vary depending on who you were seeing or the health condition you were dealing with?
- Regardless of who made the decisions in those consultations, were you comfortable with the situation, or would you have preferred to be more or less involved in decision making?

Answering these questions can help you to think about your preferences for making decisions about your healthcare — whether you generally prefer to make the decisions yourself, to give your professional responsibility for decisions, or to share decisions to some extent.

HOW TO MAKE YOUR PREFERENCES CLEAR

It is important to make clear to your healthcare professional how much you wish to be involved in decision making. This is something that needs to happen throughout a consultation, because your preferences will probably vary, depending on things such as the decision to be taken and the information you have about your condition.

- If you decide that you would prefer to give responsibility for a decision to your professional, you can say something like ‘What do you recommend?’

- If you want to share the decision, you might ask your professional to help you find more information or to discuss with you the pros and cons of various options. You could then share your feelings about the various options, so that you can make the decision together.

It may be helpful to think about the consultation as a negotiation. You and your professional share information and views; you probably agree on some points and disagree on others. Eventually, you come to a point where you, as the consumer, feel comfortable with whatever decisions are taken and with the extent of your involvement in those decisions.

EXERCISES FOR HEALTHCARE CONSUMERS

At the end of this section, there are scenarios and questions designed to help healthcare consumers and healthcare professionals put into practice the tools and information given in this principle.

Putting the principle into practice — tools for healthcare professionals

This section provides ideas on how you could work with healthcare consumers to explore their preferences for involvement in decision making.

REFLECT ON YOUR USUAL APPROACH

Think about your consultations and how decisions are usually made.

- Do you tend to simply recommend a course of action? ('paternalistic' approach)
- Do you generally expect consumers to make decisions based on the information you have given them? ('informed decision' approach)
- Do you try to involve consumers to a greater or lesser extent in making decisions? ('shared decision making' approach)
- Alternatively, is your normal style a mixture of these different approaches? If so, what is it that prompts you to use a particular approach?
- Do you feel that you are sufficiently flexible to deal with the decision-making preferences of different consumers, and in different situations?

Answering these questions provides a way to think about whether you are already exploring and supporting consumers' preferences for involvement in decision making, and whether this is an area you would like to develop.

WORK ON WAYS TO ELICIT HEALTHCARE CONSUMERS' PREFERENCES

One way to involve consumers is to ask 'What do you think?' Obviously, some people may respond to this by saying something like 'I don't know, you're the doctor'. You can respond by saying something like 'Yes, but it's your body, your health and your life. I will help you to get as much information as you want, and will give you my opinion, but I'd really like to include your views in our planning.'⁸

It may be helpful to think about the consultation as a negotiation, where you and the consumer share information and views. You might agree on some points and disagree on others, but eventually you will come to a point where the consumer feels comfortable with the decisions made and the extent of their involvement in those decisions.

EXERCISES FOR HEALTHCARE PROFESSIONALS

Below are scenarios and questions designed to help healthcare professionals and healthcare consumers put into practice the tools and information given in this principle.

Exercises for principle 2

Imagine you are in the position of the healthcare consumer or healthcare professional in the following scenarios, and think about how you might answer the questions below.

8 Adapted from Weston 2001

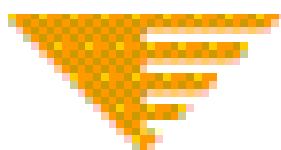
Scenario 1

Sandra is a 35-year-old woman whose mother has recently died of breast cancer. Her grandmother also died of breast cancer. Sandra read in a magazine that genetic tests can indicate whether someone has a higher than average chance of getting breast cancer. She discussed the article with her GP and, after considering the pros and cons, decided to have a test to see whether she has one of the gene mutations linked to breast cancer. The test showed that she does have the mutation, and the GP arranged for her to see a specialist.

At the consultation, the specialist explains to Sandra that some women in her position choose to have an operation to remove both breasts, and suggests that this is one option she might consider. Sandra is worried about developing breast cancer, and would like to do all she can to avoid it. However, not surprisingly, she is upset about the idea of taking the drastic step of having both breasts removed. The specialist asks Sandra to think about what she would like to do.

Scenario 2

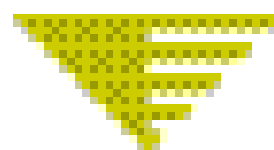
Alex is a 55-year-old director of a large company, quite used to making her own decisions. She has just been told by her GP that she has a high level of the 'bad' form of cholesterol, even though she eats what she considers a healthy diet and goes to the gym about three times a week. She is being treated for high blood pressure, has a family history of heart attacks and has recently stopped smoking. The GP suggests various options to Alex for reducing her risk of suffering a heart attack —to look at her diet and see if she could improve it, or (if necessary) to take one of the drugs called 'statins' to reduce her cholesterol level. The GP explains that statins, like all drugs, can have some side effects, and that if such treatment is required, Alex would probably have to stay on the medication forever. The GP asks Alex what she would like to do.



How much do I want to be involved in making this decision?

How could I tell the GP how much involvement I want?

Do I feel ready to make a decision, or do I need more time or more information?



How could I help this person to work out how much they would like to be involved in the decision?

How could I find out and accommodate their preferences for involvement?

How could I check whether they need more time or more information?

Find out more

CASE STUDIES

Part 2 of this toolkit includes a case study on the prostate specific antigen (PSA) test, which illustrates how preferences for involvement in deciding whether to have the test, vary.

BIBLIOGRAPHY

An asterisk * after a reference indicates that the study was a systematic review.

Bekker H, Thornton JG, Airey CM, Connelly JB, Hewison J, Lilleyman J, MacIntosh M, Maule AJ, Michie S, Pearman AD and Robinson MB (1999). Informed decision making: an annotated bibliography and systematic review. *Health Technology Assessment* 3:1–156.*

Charles C, Whelan T and Gafni A (1999). What do we mean by partnership in making decisions about treatment? *British Medical Journal* 319:780–782.

Collins S, Drew P, Watt I and Entwistle V (in press). ‘Unilateral’ and ‘bilateral’ practitioner approaches in decision-making about treatment. *Social Science and Medicine*.

Coulter A (1997). Partnerships with patients: the pros and cons of shared clinical decision-making. *Journal of Health Services Research and Policy* 2:112–121.

Degner LF and Sloan JA (1992). Decision making during serious illness: what role do patients really want to play? *Journal of Clinical Epidemiology* 45:941–950.

Deyo RA (2001). A key medical decision maker: the patient. *British Medical Journal* 323:466–467.

Elwyn G, Edwards A, Gwyn R and Grol R (1999). Towards a feasible model for shared decision making: focus group study with general practice registrars. *British Medical Journal* 319:753–756.

Entwistle V (2004). Trust and shared decision-making: an emerging research agenda. *Health Expectations* 7:271–273.

Entwistle V, Williams B, Skea Z, Maclennan G and Bhattacharya S (in press). Which surgical decisions should patients participate in and how? Reflections on women’s recollections of discussions about variants of hysterectomy. *Social Science and Medicine*.

Kravitz RL (2001). Measuring patients’ expectations and requests. *Annals of Internal Medicine* 134:881–888.

Kravitz RL and Melnikow J (2001). Engaging patients in medical decision making. *British Medical Journal* 323:584–5.

McNutt RA (2004). Shared medical decision making. Problems, process, progress. *Journal of the American Medical Association* 292:2516–2518.

Robinson A and Thomson R (2001). Variability in patient preferences for participating in medical decision making: implications for the use of decision support tools. *Quality in Health Care* 10:i34–i38.

Strull WM, Lo B and Charles G (1984). Do patients want to participate in medical decision making? *Journal of the American Medical Association* 252:2990–2994.

Towle A and Godolphin W (1999). Framework for teaching and learning informed shared decision making. *British Medical Journal* 319:766–769.

Wellard S, Lillibridge J, Beanland C and Lewis M (2003). Consumer participation in acute care settings: an Australian experience. *International Journal of Nursing Practice* 9:255–260.

Weston WW (2001). Informed and shared decision-making: the crux of patient-centred care. *Canadian Medical Association Journal* 165:438–439.

Principle 3:

Good communication depends on recognising and meeting the needs of healthcare consumers

This principle and the information supporting it are based on the references listed at the end of this section

BACKGROUND

Good communication between healthcare professionals and healthcare consumers depends on each being able to understand the other. A wide range of factors can aid or create obstacles to that understanding; for example, age, gender, social and economic circumstances, health status, education, cultural background, disability, literacy and health literacy. Failing to recognise and meet communication needs can lead to consumers:

- not understanding their medical condition and the risks and benefits of treatment options
- becoming unduly anxious about their condition and treatment options
- being unable to discuss their condition with their health professionals or contribute as much as they would like to decisions about their healthcare.

For example, a consumer cannot make informed decisions if their professional uses medical terms that they do not understand, or provides written information that is beyond their literacy or numeracy skills.

What do we mean by literacy and health literacy?

Literacy is the ability to read and write. A person who has only *basic* literacy can do very simple things, such as sign their name, whereas someone who has *functional* literacy can recognise words and phrases in specific contexts. A survey in 1996 found that about half the Australian adult population (about six million people) had 'poor' or 'very poor' literacy skills, and could not use printed materials encountered in everyday life, such as order forms and bus timetables.⁹ These findings mean that a large number of healthcare consumers may not have the skills to understand and follow medical instructions, or to use health information and community resources.

Health literacy is a form of functional literacy — it refers to a person's capacity to obtain, process and understand information needed to make appropriate health decisions; that is, their ability to understand and act on health information. For example, someone who is not health literate might not be able to understand written instructions for how to take a medication or directions to find

continued »

9 ABS 1996

continued »

a pathology laboratory; similarly, they might not be able to read and understand informed consent forms. Poor health literacy can be linked to poor health status, and this combination of factors can be connected with worse health outcomes.

Health literacy requires both functional literacy and numeracy, because understanding health information also involves dealing with numbers; for example, in working out what dose of medication to take. However, being health literate means more than simply being able to read and use numbers — someone who is health literate is likely to understand and use health information so that they can make the best decisions for their situation. Even some well-educated people can have problems with health literacy.

Health literacy also has a cultural dimension, in that some cultures do not believe 'accepted' medical explanations (rather than not understanding them).

What this means for healthcare consumers

It is important that you are told about your health condition and your treatment options in a way that you can understand. It is also important that your views are heard. If English is not your first language, you can ask for a qualified health interpreter if you need one — your treatment should not be refused or unreasonably delayed because of the need for an interpreter. Having a qualified health interpreter (rather than using a family member or friend) is important because interpreting is a skilled task, because of issues such as medical terminology. Using a qualified health interpreter also helps to ensure your privacy.

If you have communication difficulties at the time of the consultation, you should let your healthcare professional know this. For example, tell the person if you cannot hear them properly, need to lip read, are feeling too ill or anxious to take in what they are telling you, or cannot understand the verbal and written information they have given you. The better your professional understands your communication difficulties, the more they can do to overcome them.

You also need to be aware that your professional may themselves have communication difficulties. Healthcare professionals come from a variety of backgrounds, and have different training and experience in the skills of communication. Like you, they are affected by time pressures and may be distracted by personal issues. Also, like all people, professionals vary in their sensitivity and their ability to understand someone else's feelings.

The *Tools for healthcare consumers* section of this principle provides ideas to help you to work out whether you have any special communication needs, and how you can work with your professional to deal with these needs.

What this means for healthcare professionals

Many of the healthcare consumers that you see have special communication needs; for example, those who:

- are elderly
- have a different cultural background from you (particularly those whose first language is not English)
- have visual or hearing impairments
- have had minimal education
- have a learning disability
- have poor literacy or numeracy
- have poor health literacy (note: all of the above factors can contribute to poor health literacy)
- depend on illicit drugs or alcohol.

Where necessary, you might consider including the person's carer or advocate (for example in the case of children, young people and some elderly people), to help overcome communication problems.

Even consumers who normally communicate well may have difficulties if they are affected by their condition, medication, or feelings about their illness. For example, someone who is anxious, embarrassed or in denial about their medical condition may find it hard to talk to you or to take in the information that you are giving them.

Think about your own consultations — what strategies are you using to recognise and support consumers with special communication needs?

If you would like to improve your skills in this area, the *Tools for healthcare professionals* section of this principle provides ideas on how you can do this.

EXAMPLES

The following studies and stories illustrate some aspects of the principle that good communication depends on recognising and meeting the needs of healthcare consumers.

Studies

Taking cultural differences into account requires different approaches

A study in Sydney looked at 36 people with cancer and 12 of their relatives, all of whom were born in China, Singapore or Malaysia. The participants believed psychosocial factors were important in fighting disease; thus, most preferred their healthcare professionals not to disclose a poor prognosis, so that they could continue to feel hopeful and optimistic. Generally, they preferred their spouse or other close family members to be told of a poor prognosis first, so that the family could tell the professional how best to approach the issue with the consumer. All but one of the participants emphasised the importance of fully informing and involving the family.

continued »

continued »

The consumers in this study wanted their professionals to be open minded about Eastern treatments, and to collaborate with them on developing a combined treatment regimen. They valued information presented in a culturally sensitive manner, which included using a professional interpreter where appropriate. Even participants with good skills in English said they had difficulty understanding medical jargon, and needed professional interpreter services.

Source: Huang et al 1999.

Healthcare professionals need to change their attitudes to meet the needs of consumers with learning disabilities

A systematic review looked at studies of how women with learning disabilities could be helped to consent to, and be less anxious about, a cervical smear test. The few relevant studies showed a low uptake of the screening test by this group of healthcare consumers, because of factors such as poor literacy skills, attitudes among consumers and professionals, anxiety on the part of the women, professionals' concerns about the consumers' capacity to consent, and assumptions by professionals that women with learning disabilities are sexually inactive. The reviewer concluded that professionals need to change their attitudes to meet the needs of these consumers, to provide them with the support needed to make informed decisions.

Source: Broughton 2002.

Poor health literacy creates obstacles to understanding health, illness and treatment

Researchers in the United States looked at health literacy and health-related knowledge among about 300 people living with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). Using a standard test, about 1 in 5 of the participants was found to have poor functional health literacy. The consumers with poor health literacy were more likely than their health-literate counterparts to be in poor health, to have detectable virus and to see their doctor at least once a month because of health problems. These consumers were also less involved in their healthcare, with their doctors less likely to ask their opinion about their treatment or explain things to them in ways that they could understand. They had poorer knowledge and understanding of the status of their HIV illness than their health literate counterparts, and more misconceptions about how HIV treatments affect risk of HIV transmission. This group of consumers was therefore more likely to be infectious and less likely to realise this fact. The authors concluded that poor health literacy hinders a person's understanding of their health, illness and treatments, and increases the danger of potential transmission of treatment-resistant strains of HIV.

Source: Kalichman et al 2000.

Putting the principle into practice — tools for healthcare consumers

This section provides ideas for how you might:

- help your healthcare professional to communicate more effectively with you
- talk to your professional about any cultural or spiritual matters that you would like them to take into account
- ask for a qualified health interpreter if you need one.

HELP YOUR HEALTHCARE PROFESSIONAL TO COMMUNICATE MORE EFFECTIVELY WITH YOU

If you do not understand what your professional is talking about, or the written information they have given you, tell them — for example, you might say ‘Can you say that again?’ or ‘Can you write that down for me?’ The more your professional knows about you, the better they can communicate with you. For example, if they know that you have a hearing problem, they could help you to lip read by speaking more slowly and clearly, looking at you when speaking and providing good lighting so that you can see them easily. Where it would be helpful to do so, you could ask your professional to write things down, give you a videotape or leaflet, or tell you about websites where you can find more information.

If you find it difficult to communicate, consider taking someone with you to the consultation, such as your partner, family member, carer or friend. Similarly, if you know that you may be given bad news or lots of information, take someone with you, because you will probably not be able to take in everything discussed during the consultation. The other person can be your ‘second set of ears’, they can also act as a scribe, taking notes so that you feel free to listen. After the consultation, you can go over with them what was discussed. A friend, carer or family member can also act as your advocate if necessary.

If you think that a friend or someone in your family may have difficulty communicating with healthcare professionals, you can offer to go with them to their consultations.

If you have an issue you need to raise but are concerned that it may take a long time, you can say something such as ‘I’d like to talk about X, but do you have the time today?’ Either your professional will have the time, in which case this gives you an opportunity to talk without feeling pressured; or they will be too

busy, in which case you could suggest that you make a double appointment for the next consultation, so that the discussion will be less rushed.

Other issues that might be important to you (and which it is helpful for your professional to be aware of) are:

- involving family, carers or friends in decision making
- having plenty of time for decision making (you may feel that you need weeks or months)
- having an appropriate environment for decision making.

EXPLAIN ANY CULTURAL OR SPIRITUAL PREFERENCES

Tell your healthcare professional about any cultural or spiritual matters you think they may not be aware of, but need to know about to treat you effectively. This will allow them to take these matters into account when giving you recommendations or helping you to work out the best treatment option for you. In the 'Examples' section of this principle, the study of consumers born in China, Singapore or Malaysia and now living in Sydney shows the importance of letting your professional know about your cultural or spiritual preferences. Similar issues are raised on the website *Sharing the True Stories*, which uses the example of communication between health staff and Yolnu (Aboriginal people from northeast Arnhemland) to support improved communication between health staff and Indigenous clients.¹⁰ For example, the site advocates mutual respect and trust, and emphasises that the consumer's story has as much weight in the consultation as the medical story.

ASK FOR AN INTERPRETER IF NECESSARY

If someone in your family has difficulty with English, ask for a qualified health interpreter. Even someone who is quite proficient in English in everyday situations may have trouble understanding medical terms, and may benefit from having an interpreter. Since interpreting is a skill, it is best done by someone who is qualified. Professional health interpreters can also give consumers privacy, as some people do not wish to share their medical problem with family members or friends. If there are no health interpreters in your area, you can use a telephone interpreting service (the *Find out more* section of this principle has details of such services, and of the availability of translated materials).

¹⁰ <http://www.sharingtruestories.com>

EXERCISES FOR HEALTHCARE CONSUMERS

At the end of this section there are scenarios and questions designed to help healthcare consumers and healthcare professionals put into practice the tools and information given in this principle.

Putting the principle into practice — tools for healthcare professionals

This section provides ideas on how to:

- communicate more effectively with healthcare consumers
- understand and accommodate cultural and spiritual differences
- recognise and overcome any communication barriers that might be present.

COMMUNICATING MORE EFFECTIVELY WITH HEALTHCARE CONSUMERS

To improve your skills in identifying and communicating with consumers who have communication difficulties, there are many strategies you can use. For example, many people who have difficulty in reading, writing or arithmetic are skilled at hiding their illiteracy, because they feel embarrassed and ashamed about it. However, you can be alert for clues that indicate a possible problem, such as the person immediately putting aside any written material you give them, holding it the wrong way up or saying 'I'll read it later'. You can also be alert for clues that indicate the person is literate or has understood information; for example, they may ask relevant questions, make comments about what they have learned, or bring in material that they have found on the internet.

Below are some strategies that you may find helpful in communicating with all consumers, but particularly with those who may have communication difficulties. Many of these strategies are summarised in a paper discussing how nurses can adapt their teaching techniques to the particular needs of patients with literacy or language difficulties (Dreger and Trembeck 2002).

Build rapport — Effective communication depends on good rapport between professionals and consumers. Strategies to build rapport include being compassionate and sensitive, and having an interest in the person, rather than just their health issue. Other factors that help are being accepting, understanding and nonjudgmental, and not talking down to the person.

The NHMRC publication *Communicating with Patients: Advice for Medical Practitioners* (NHMRC 2004a) describes rapport and active listening as the foundations of good communication, and gives advice on how to establish rapport at the start of a consultation.

Present information clearly — Techniques to present information clearly, and thus increase understanding, include:

- using familiar words and avoiding medical jargon (for example, saying 'low blood sugar' rather than 'hypoglycaemia')
- clearly describing what the consumer is required to do and the relevance of the treatment to them; this is particularly important in helping consumers to provide fully informed consent
- using alternatives to written materials, such as videotapes, audiotapes, illustrated materials or decision aids (these tools can be helpful even for consumers who do not have obvious problems with literacy or numeracy)
- for people with impaired hearing — speaking slowly and clearly, and looking directly at the person while speaking to them
- for people with impaired sight — using special materials, such as texts in large print or Braille, where available
- for people with poor health literacy — using videos or illustrated material as an alternative to written information.

Demonstrate and ask for feedback — If someone appears to have a problem with literacy or language, a useful strategy is to demonstrate and ask for feedback (sometimes referred to as the 'show-me' technique), rather than simply giving verbal or written instructions. For example, when giving someone an asthma inhaler, you might show them how it is used, then ask them to show you how to do it, to check that they have understood your instructions. If it is evident that the consumer has not understood you, and that person is not from an English-speaking background, you may need to use an interpreter (discussed below).

Check understanding — Whether or not a consumer appears to have special communication needs, it is worth checking for understanding through interactive questioning. For example, you might ask the person to rephrase the main points of the information you have given them (although it is important to be empathic and not condescending when doing this).

Respect and take into account cultural beliefs and values — How do your own cultural beliefs and practices affect your life and clinical practice? Could you learn more about the cultural beliefs

and practices of the different groups of consumers you deal with regularly? If so, it is a good idea to ask those consumer groups for feedback and input, to avoid making incorrect assumptions. It is important to use words that show respect for the consumer's culture and personal beliefs.

The Multicultural Equity and Access Program in Melbourne has produced a *Home and Personal Care Kit* (MEAP 2004), which is a series of cultural and religious profiles intended to help in providing culturally sensitive care and effective communication.¹¹ Although the document is primarily designed for use by home and personal care workers, and by assessment staff, it would also be useful for healthcare professionals.

Useful resources for professionals working with Aboriginal and Torres Strait Islander people include:

- the *Cultural Respect Framework* (AHMAC 2004)
- *Sharing the True Stories*, a website that supports improved communication between health staff and Indigenous clients
- a series of publications on pregnancy and postnatal care, produced by Illawarra Health
- an article on lessons learned from more than four years of clinical experience in the remote Australian district of east Arnhemland, describing the importance of gaining trust and credibility with a community, approaches to gain that trust, and strategies to overcome language and world-view barriers to good communication (Bryce 2002).

Details of these resources are given in the *Find out more* section at the end of this principle.

The study of healthcare consumers born in China, Malaysia or Singapore (Huang et al 1999, described in the *Examples* section of this principle) illustrates the importance of taking cultural beliefs and values into account. The consumers in that study wanted their family to be told of the prognosis before they were told. As this situation differs from usual practice in Australia, it needs additional communication channels; for example, in that study, some consultations were audiotaped, so that family members unable to attend could listen to them later. This situation also requires careful thought about the order and timing of information provision. Potential conflicts are nearly always resolved through further discussion in a setting of mutual respect and understanding,

¹¹ <http://www.miceastmelb.com.au/documents/mep/HC&PCGuide.pdf>

although this process may take time. The consumers in this study also expected and valued firm recommendations for treatment. Again, this is at odds with the current emphasis on informed consent and active patient involvement in decision making, an approach that these particular consumers may interpret as incompetence or lack of caring.

Providing an interpreter if necessary — Consumers whose first language is not English may need an interpreter, because even people who are reasonably proficient in English may struggle to understand medical terms and jargon. Since interpreting is a skilled task, a qualified health interpreter is needed, rather than using family members or friends; having a qualified person to interpret also helps to protect the consumer's privacy, if desired. In areas where an interpreter is not available in person, telephone interpreting services may be helpful (the *Find out more* section of this principle has details of such services, and of the availability of translated materials).

IMPROVING CULTURAL COMPETENCE

Cultural competence can be defined as the behaviours, attitudes and policies that allow a system, agency or people to work effectively with people from different cultural backgrounds. Cultural competence is much more than awareness of cultural difficulties, as it focuses on the capacity to improve health and wellbeing by integrating culture into healthcare delivery (NHMRC 2005). If you wish to improve your cultural competence, a good place to start is to reflect on how your own cultural identity has been shaped, and to recognise the impact that culture has on your healthcare practice. Taking this step will help you to develop greater sensitivities and practices to better meet your consumers' social, cultural and linguistic needs.

EXERCISES FOR HEALTHCARE PROFESSIONALS

Below are scenarios and questions designed to help healthcare professionals and healthcare consumers put into practice the tools and information given in this principle.

Exercises for principle 3

Imagine you are in the position of the healthcare consumer or healthcare professional in the following scenarios, and think about how you might answer the questions below. To think about communication issues in a cross-cultural setting, it may be useful to also consider how these scenarios (and those in the other principles) might be different if either the consumer or the professional was from a culturally and linguistically diverse background.

Scenario 1

Carla is a 21-year-old woman visiting her GP because she has found a lump in her right breast. Her background and culture are different from those of most people born in Australia. After an examination, the GP, who is female, tells Carla that she wants to refer her to a particular consultant for further investigation, because he will be able to tell her whether the lump is malignant. The GP says that this consultant is highly recommended. Carla does not want to be treated by a male healthcare professional, but she is worried about the lump and would like to have it investigated.

Scenario 2

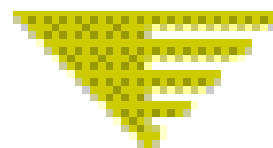
Anna is a 50-year-old Aboriginal woman who visits a nurse practitioner after being recalled for a check-up for her non-insulin-dependent diabetes mellitus. Anna is obese and has mild hypertension, and a blood test shows that her blood glucose levels are poorly controlled. She is on the highest doses of oral anti-diabetic medications, and most of the time she takes the medication as recommended. The nurse practitioner explains to Anna that she will need to start insulin injections to properly control her diabetes, but Anna is reluctant to do so.



Do I have particular cultural issues that are relevant in this consultation?

Are those issues affecting my feelings about the suggested options for treatment?

What could I do to let the healthcare professional know about those issues?



How could I explore the source of this person's anxiety?

Is there anything in what the person has told me that has cultural origins?

If so, how can I best meet the person's needs?

Find out more

CASE STUDIES

The example of a prostate-specific antigen (PSA) screening test in Part 2 of this toolkit shows how the test is affected by factors such as age, culture, education, disability and literacy.

RESOURCES

All You Need to Know About a Healthy Pregnancy for a Healthy Baby — An Aboriginal Personal Pregnancy Handbook

A booklet produced by Illawarra Health, to promote healthy pregnancy and breastfeeding among Aboriginal women.

Address: Available from Division of Population Health and Planning, South Eastern Sydney and from Illawara Health, Division of Population Health and Planning, Suite 3d, 145–149 King St, Warrawong, NSW 2502

Phone: 02 4255 2200

Home and Personal Care Kit

Produced by the Multicultural Equity and Access Program's Migrant Information Centre to help service providers in culturally sensitive care and effective communication with people of culturally and linguistically diverse backgrounds.

Address: 333 Mitcham Road, Mitcham, VIC 3132

Phone: 03 9873 1666

Website: <http://www.miceastmelb.com.au/documents/mep/HC&PCGuide.pdf>

Koori Women's 'Baby Blues'

Illawara Health has published a pamphlet (*Koori Women's 'Baby Blues' — Postnatal Depression in the Aboriginal Community*) and a booklet (*Koori Women's 'Baby Blues' — A Project about Aboriginal Women and their Feelings after having a Baby*) to raise awareness of postnatal depression in Aboriginal communities in the Illawara and Shoalhaven.

Address: Available from Division of Population Health and Planning, South Eastern Sydney and from Illawara Health, Division of Population Health and Planning, Suite 3d, 145–149 King St, Warrawong, NSW 2502

Phone: 02 4255 2200

Resources for Health Literacy Information and Publications

Factsheet produced by the Center for Health Care Strategies in the United States, containing a list of materials developed for particular conditions and groups of consumers.

Address: P.O. Box 3469, Princeton, NJ 08543-3469, United States

Phone: (609) 895 8101

Website: <http://www.chcs.org> (see *Resources for Health Literacy Information and Publications* at http://www.chcs.org/publications3960/publications_show.htm?doc_id=291711)

Sharing the True Stories

Website (still in development) aims to improve communication between health staff and Aboriginal and Torres Strait Islander clients; currently focuses on the Yolnu from northeast Arnhemland, but will expand to other areas of service delivery and other language groups.

Phone: 08 8941 1162

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

Translating and interpreting service

The Health Insurance Commission has a translating/interpreting service on its *Your Health* website. The New South Wales Multicultural Health Communication Service (see below under *Relevant organisations and websites*) also has a Health Care Interpreter Service.

Phone: 131 450

Website: <http://www.hic.gov.au/yourhealth/>

RELEVANT ORGANISATIONS AND WEBSITES

Center for Health Care Strategies (United States)

The centre aims to induce individual states, health plans and consumer groups, through technical assistance and training, to engage in activities to improve quality of healthcare.

Address: P.O. Box 3469, Princeton, NJ 08543-3469, United States

Phone: (609) 895-8101

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

Multicultural Equity and Access Program

This program, which is funded by the Victorian Department of Human Services, aims to develop and implement strategies to improve access to home and community care funded services in the Eastern Region of Melbourne, for people from culturally and linguistically diverse backgrounds.

Address: 333 Mitcham Road, Mitcham, VIC 3132

Phone: 03 9873 1666

Website: <http://www.miceastmelb.com.au/meap.htm>

National Health Service Cancer Screening Programme (United Kingdom)

This programme provides a range of information for healthcare consumers on screening for breast, cervical, prostate and bowel cancer. Materials available from the website include:

- a leaflet entitled *Breast Screening: The Facts* — available in 18 languages
- a leaflet entitled *Cervical Screening: The Facts* — available in 20 languages
- picture leaflets for women with learning disabilities, to tell them about breast and cervical screening, and where they can find more information
- an information sheet for men considering a PSA test
- information on bowel cancer (the signs and symptoms, how many people get the disease, how many people die of it and what the risk factors are).

Address: Fulwood House, Old Fulwood Road, Sheffield S10 3TH, United Kingdom

Phone: (0114) 271 1060

Website: <http://www.cancerscreening.nhs.uk>

Multicultural Health Communication Service

The New South Wales Multicultural Health Communication Service assists healthcare professionals to communicate with non-English speaking communities throughout the state. The site includes more than 12,000 health resources in 35 languages (with new publications added regularly), links to related websites and to multilingual resources produced by other services. The organisation also has a Health Care Interpreter Service

Phone: 02 9382 7516

Website: <http://www.mhcs.health.nsw.gov.au/>

Interpreter service:

Phone: 02 9515 3222

Website: <http://www.mhcs.health.nsw.gov.au/health-public-affairs/mhcs/publications/4300.html>

BIBLIOGRAPHY

An asterisk * after a reference indicates that the study was a systematic review.

AHMAC (Australian Health Ministers' Advisory Council (2004). *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009*, Department of Health, South Australia.

AMA (American Medical Association) (1999). Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, AMA. *Journal of the American Medical Association* 281:552–557.

Arouni AJ and Rich EC (2003). Physician gender and patient care. *Journal of Gender-Specific Medicine* 6:24–30.

Australian Bureau of Statistics (ABS) (1996). *Aspects of Literacy: Assessed Skill Levels*. Canberra.

Bolden GB (2000). Towards understanding practices of medical interpreting: interpreters' involvement in history taking. *Discourse Studies* 2:387–419.

Broughton S (2002). A review of the literature: interventions to maximize capacity to consent and reduce anxiety of women with learning disabilities preparing for a cervical smear test. *Health Services Management Research* 15:173–85.*

Bryce S (2002). Lessons learnt from East Arnhem Land. Improving adherence to chronic disease treatments. *Australian Family Physician* 31:617–621.

Dreger V and Tremback T (2002). Optimize patient health by treating literacy and language barriers. *Association of Operating Room Nurses Journal* 75:280–293.

Gazmararian JA, Williams MV, Peel J and Baker DW (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling* 51:267–275.

Hall JA and Roter DL (1998). Medical communication and gender: a summary of research. *Journal of Gender-Specific Medicine* 1:39–42.

Huang X, Butow P, Meiser B and Goldstein D (1999). Attitudes and information needs of Chinese migrant cancer patients and their relatives. *Australian and New Zealand Journal of Medicine* 29:207–213.

Kakai H, Maskarinec G, Shumay DM, Tatsumura Y and Tasaki K (2003). Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. *Social Science and Medicine* 56:851–862.

Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J and Rompa D (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine* 18:325–331.

Kaplan RM, Hammel B and Schimmel LE (1985). Patient information processing and the decision to accept treatment. *Journal of Social Behavior and Personality* 1:113–120.

Latham CE (1998). Is there data to support the concept that educated, empowered patients have better outcomes? *Journal of the American Society of Nephrology* 9:S141–144.

Malone C (2003). Provision of information to patients in an NHS IVF unit. *Human Fertility* 6:26–29.

McCray AT (2005). Promoting health literacy. *Journal of the American Medical Information Association* 12:152–163.

MEAP (Multicultural Equity and Access Program) (2004). *Home and Personal Care Kit: Cultural and Religious Profiles to Assist in Providing Culturally Sensitive Care and Effective Communication*. Home and Community Care and Migrant Information Centre, Melbourne.

NHMRC (National Health and Medical Research Council) (2004a). *Communicating with Patients: Advice for medical practitioners*. Commonwealth of Australia, NHMRC, Canberra.

NHMRC (National Health and Medical Research Council) (2006). *Cultural Competency in Health: a guide for policy, partnerships and participation*, NHMRC, Canberra.

Parker R, Baker DW, Williams MV and Nurss JR (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine* 10:537–541.

Poses RM, De Saintonge MC, McClish DK, Smith WR, Huber EC, Clemo LW, Schmitt BP, Alexander-Forti D, Racht EM, Colenda CC and Centor RM (1998). An international comparison of physicians' judgements of outcome rates of cardiac procedures and attitudes towards risk, uncertainty, justifiability, and regret. *Medical Decision Making* 18:131–140.

Roberts C, Sarangi S and Moss B (2004). Presentation of self and symptoms in primary care consultations involving patients from non-English speaking backgrounds. *Communication and Medicine* 1: 159–169.

Royal Australasian College of Physicians (RACP) (2001). *An Introduction to Cultural Competency*. RACP (revised 2004).

Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, Palacios J, Sullivan GD and Bindman AB (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association* 288:475–482.

Vastag B (2004). Low health literacy called a major problem. *Journal of the American Medical Association* 291:2181–2182.

Williams M, Baker DW, Parker RM and Nurss JR (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Archives of Internal Medicine* 158:166–172.

Principle 4:

Perceptions of risks and benefits are complex, and healthcare consumers and healthcare professionals may have different priorities

This principle and the information supporting it are based on the references listed at the end of this section. The text of this principle largely refers to risks, but similar issues apply to the perceptions of benefits.

BACKGROUND

Talking about risk is rarely simple, because people's attitudes towards risk and their perceptions of risk are influenced by many factors. The word 'risk' in this situation refers to:

- the harm that could occur if a condition is left untreated
- the side effects and dangers that could occur during or after a health treatment or test.

It also refers to the likelihood of these risks occurring, and how serious they may be if they do.

Perceptions of risk are built up over time, and are shaped by things like personal experiences, social networks, emotions, education and media reporting. This means that different people will interpret risks and benefits very differently, even when good scientific information is available. The way that healthcare professionals see the risks and benefits of treatment options will often differ from the way that healthcare consumers see those same risks and benefits in relation to their own health.

Different perceptions of risk

The main difference between the way that scientists (including healthcare professionals) and the public generally think about risk can be summarised as follows:

- *Scientific concept of risk* — is concerned with the mathematical probability of something happening within a whole population group (for example, the chance of breast cancer in women over 50) and is supported by statistical information. This way of assessing risk is important, but it is objective, impersonal and deals with populations rather than individuals.
- *Everyday concept of risk* — is bound up in the individual's concerns, anxieties and fears about the future. This way of thinking about risk is very personal, and is therefore influenced more by individual issues and priorities than by statistical probabilities.

When consumers and professionals exchange information about health risks, the exchange is never neutral — each side brings their own perspective. For example, professionals may talk about the ‘drawbacks’ of a particular option rather than using the more alarming term ‘risks’, and consumers may pick up on information about risks that they see as relevant, but may miss other points in the exchange. The situation is further complicated by the many kinds of information consumers might want to know about risks, such as what might happen and when, how likely it is, how bad it might be and how long any effects might last.

Perceptions of risk need to be expressed openly in conversations between consumers and professionals, so that both can understand the other’s perspective and arrive at a decision that best meets the consumer’s needs. This is particularly important in situations where there is more than one feasible option, since different consumers may value the advantages and disadvantages of various options differently. It is also important in the many situations where we lack precise scientific information about the risks and benefits of the options available.

What this means for healthcare consumers

As with all aspects of life, you bring to discussions about your health many conscious and subconscious anxieties, fears, priorities and lifestyle preferences. These factors affect the way that you react to information that your healthcare professional provides about the risks and benefits of your healthcare options.

For example, if you have a medical condition for which there is more than one feasible treatment option, the path you choose might depend on things such as:

- how much the condition affects your everyday life
- how important the possible drawbacks of the various options are to you
- what you have read in the paper or on the internet
- what a friend did in a similar situation
- worries about taking time away from your work, family or community
- financial considerations.

How you see the risks and benefits of different options may vary from how your professional sees them. This means that you need to work together to make sure that your professional understands what matters to you, and can help you to make the decision that best suits you.

The *Tools for healthcare consumers* section of this principle provides ideas on how you can do this.

What this means for healthcare professionals

Successful communication depends on both you and the healthcare consumer recognising and respecting the other's perspectives about risks and benefits. Whereas you have scientific expertise and an understanding of probabilities and statistics related to populations, the consumer knows most about their own anxieties, fears and lifestyle preferences in relation to their medical condition. Scientific evidence of risk and benefit, however compelling, is only part of the story for consumers, who bring other lifestyle considerations and priorities to making decisions about their health.

You may find that understanding how an individual views specific health outcomes helps you to put their choices (which may not always seem logical) into context. It may also help you to provide scientific evidence in a way that is relevant to the consumer's unique perspective, so that you have a shared understanding of the issues.

The *Tools for healthcare professionals* section for this principle has ideas on how you can encourage consumers to share their feelings about risks and benefits.

EXAMPLES

The following studies and stories illustrate some aspects of the principle that perceptions of risk are complex, and that differing perceptions of risk may result in differing priorities between consumers and professionals for tests and treatment options.

Studies

Variation in treatment preferences of healthcare consumers and healthcare professionals

A review of studies about treatment preferences found that consumers and professionals often differ in their preferences for treatment; however, the direction and size of the differences vary, depending on the clinical condition. For example, in the context of heart conditions, professionals are more likely than consumers to favour drug treatments. In contrast, in the context of acute respiratory illness, consumers often request drug treatments (that is, antibiotics) in situations where professionals would view such treatments as inappropriate.

Source: Montgomery and Fahey 2001.

Emotions are more important than numbers

Researchers in France asked 52 people to rate various scenarios about potentially harmful substances (for example, an industrial accident) in terms of their severity. Each scenario described:

- the seriousness of the risk posed by the substance (the 'dread' factor)
- the number of people it might affect
- the level of expert knowledge about its risk.

Participants' assessment of the risk was influenced more by the 'dread' factor than by the number of people likely to be affected or the level of knowledge about the risk, suggesting that emotions play a greater part than numbers in perceptions of risk.

Source: Mullet et al 2004.

continued »

continued »

Many factors influence choice

A study in Tasmania asked 14 women in their 40s about their reasons for choosing to participate in breast cancer screening, which is primarily aimed at older women. Reasons for participating varied, but there were three main themes: fear of breast cancer, trust in technology, and taking responsibility for health. Media coverage was also an important factor. Information on the benefits of screening did not appear to have been a factor in the decision to be screened.

Source: Willis and Baxter 2003.

High risk of pain preferred to low risk of death

A study in the United States looked at the views of 36 consumers on treatment options for deep-vein thrombosis. Options for treatment were heparin alone or heparin plus streptokinase. Adverse effects of treatment range from a mild-to-severe swelling in the leg, to bleeding in the brain (leading to stroke or death). Consumers preferred to accept the high risk of a painful, swollen leg due to heparin alone, rather than to take the small risk of stroke and death from streptokinase plus heparin.

Source: O'Meara et al 1994.

Putting the principle into practice — tools for healthcare consumers

You and your healthcare professional may have different views about the importance of certain risks and benefits. For example, if you have small children, you might prefer a treatment option that means a slower recovery from a medical problem but allows you to stay home, rather than one that would mean a quicker recovery but involves going to hospital. On the other hand, the professional may see the option with the quickest recovery time as the preferred choice.

Your preferences are as important as any scientific knowledge that your professional may have, but that person can only take your preferences into account if you make them clear. Your professional is more likely to be supportive if you explain why a particular option is better for you. In the above example of preferring an option that means a slower recovery, your professional would understand this choice better if they realise that being able to stay home with your children is an important factor in making your decision.

EXERCISES FOR HEALTHCARE CONSUMERS

At the end of this section there are scenarios and questions designed to help healthcare consumers and healthcare professionals put into practice the tools and information given in this principle.

Putting the principle into practice — tools for healthcare professionals

Views of the risks and benefits associated with a particular course of action may differ between healthcare consumers and healthcare professionals, but both views are important, because only the consumer knows what the various options mean to them. For example, in the case of removing the prostate to improve the chance of survival from prostate cancer, only the person involved will know whether this benefit outweighs the increased chance of impotence or incontinence (or both) as a result of the operation.

To understand the consumer's perspective, it may be helpful to explore what types of factors are influencing their decision. For example, someone who is concerned about taking time off work may prefer to take a riskier treatment option that will allow them to return to work within days, rather than a less risky option that means having weeks off work. A helpful attitude in this situation is to be open and honest, and to treat consumers as partners in weighing up the options.

EXERCISES FOR HEALTHCARE PROFESSIONALS

Below are scenarios and questions designed to help healthcare professionals and healthcare consumers put into practice the tools and information given in this principle.

Exercises for principle 4

Imagine you are in the position of the healthcare consumer or healthcare professional in the following scenarios, and think about how you might answer the questions below.

Scenario 1

Antonio is a slightly overweight 50-year-old man, with a 20-a-day smoking habit, who is visiting his GP for his annual influenza shot. The GP checks Antonio's blood pressure and finds that it is high.

The GP explains to Antonio that he has a high risk of having a heart attack or stroke, given his age, weight, smoking habit and blood pressure. As on previous visits, the GP recommends that Antonio stop smoking, and suggests he try calling the 'Quitline'¹², to get support and advice on how to give up his habit. On this visit, the GP also suggests that Antonio start taking half an aspirin every day, to reduce the risk of a heart attack or stroke.

continued »

¹² Phone: 137 848 (Quitline)

continued »

Antonio is willing to contact the 'Quitline', because his wife recently gave up smoking and has been encouraging him to do the same. However, he is less sure about the aspirin, as it gives him a stomach ache when he takes it, and at the moment he does not feel unwell.

Scenario 2

Joe is a 65-year-old man who has been referred to an orthopaedic surgeon because of difficulty with walking. The surgeon recommends to Joe that he have a hip replacement. Joe's wife does not drive, and the couple need a car to get to the shops and to visit family and friends. Although he is very concerned about not being able to drive for some time after the operation, Joe has not raised his concerns with the surgeon, as he does not want to bother him with personal issues.

Scenario 3

Sonja is a 40-year-old woman visiting her GP about a throat infection. While she is with the GP, she wonders whether to raise the issue of her 14-year-old daughter's size — the girl is overweight and Sonja thinks that she may even be obese. There has been a lot of information in the press about childhood obesity and the health problems it can cause in later life, and Sonja would like her daughter to be a healthier weight.

Sonja is not sure if she should say anything, because she is concerned that making an issue of her daughter's weight might lead to the child developing an eating disorder. This concern is particularly important for Sonja because a girl from her daughter's school recently went into hospital suffering from anorexia nervosa. At the moment, the daughter does not seem to be bothered by her size — she is doing well at school, has plenty of friends and enjoys an active social life. Sonja is in two minds about whether to mention her worries to the GP.

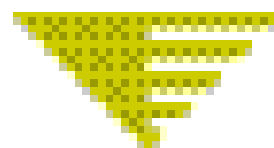


Which of the risks and benefits are most real and relevant to me?

What does a high risk mean to me?

What are my main priorities?

How can we reach agreement on a course of action that seems right for me?



Might this person see the risks and benefits differently from me?

How could I encourage them to say how they see the risks and benefits?

How can we reach agreement on a course of action that seems right for this person?

Find out more

CASE STUDIES

Part 2 of this toolkit includes case studies that illustrate how healthcare consumers may vary in their views about a particular risk.

OTHER RELEVANT PRINCIPLES

Principle 5 *Information on risks and benefits needs to be comprehensive and accessible*, provides information about communicating risks and benefits.

BIBLIOGRAPHY

- Edwards A (2003). Communicating risks. *British Medical Journal* 327:691–692.
- Edwards A and Elwyn G (2001a). Risks — listen and don't mislead. *British Journal of General Practice* 51:259–260.
- Epstein RM, Alpes BS and Qill TE (2004). Communicating evidence for participatory decision making. *Journal of the American Medical Association* 291:2359–2365.
- Kassirer JP (1994). Incorporating patients' preferences into medical decisions. *New England Journal of Medicine* 330:1895–1896.
- Lloyd AJ (2001). The extent of patients' understanding of the risk of treatments. *Quality in Health Care* 10:i14–i18.
- Montgomery AA and Fahey T (2001). How do patients' treatment preferences compare with those of clinicians? *Quality in Health Care* 10:i39–i43.
- Mullet E, Ciudad N and Riviere-Shafighi S (2004). Cognitive processes involved in the assessment of health hazards' severity. *Health Risk and Society* 6: 277–288.
- O'Meara JJ, McNutt RA, Evans AT, Moore SW and Downs SM (1994). A decision analysis of streptokinase plus heparin as compared with heparin alone for deep-vein thrombosis. *New England Journal of Medicine* 330:1864–1869.

Rakow T (2001). Differences in belief about likely outcomes account for differences in doctors' treatment preferences: but what accounts for the differences in belief? *Quality in Health Care* 10: i44–i49.

Thornton H (2003). Patients' understanding of risk. *British Medical Journal* 327:693–694.

Willis K and Baxter J (2003). Trusting technology: women aged 40–49 years participating in screening for breast cancer — an exploratory study. *Australian and New Zealand Journal of Public Health* 27:282–286.

Principle 5:

Information on risks and benefits needs to be comprehensive and accessible

This principle and the information supporting it are based on the references listed at the end of this section

BACKGROUND

Almost every health decision, including the choice not to have a treatment or test, has some associated benefits and risks. Healthcare consumers need comprehensive information on these risks and benefits, given in a way that they can understand. However, there are many factors — outlined below — that make it difficult to communicate risks and benefits in a way that is objective, useful and unbiased.

EMOTIONS, LANGUAGE, IMAGES AND PERCEPTIONS

Sharing information about risk and benefits can make both consumers and professionals feel anxious, making communication between them difficult. Also, discussion about risks and benefits between two people is necessarily subjective and personal, because everyone interprets language differently. For example, we do not have standard terms to describe risks, so different professionals may mean different things when they use words like 'high risk' or 'very low risk'. The same is true to some extent for visual materials, such as pictures and graphs, and different people may interpret these differently.

RELEVANCE OF INFORMATION

Information about risks and benefits can be particularly difficult to understand if the person has no previous experience to compare it with. For example, if the risk of a treatment failing is given as 20%, consumers may not know whether this is a relatively high or a relatively low risk, and may therefore find the information difficult to interpret. Another issue is how information on 'average' risk applies to individual consumers. Thus, risk information needs to be relevant and put into a familiar context.

AMOUNT OF INFORMATION

The quality of information given and the way in which it is presented is probably more important than the amount. Although most consumers prefer to have access to more, rather than less, information about risks and benefits, too much information can be overwhelming, particularly if the person does not see it as relevant.

UNCERTAINTY

Some risks can be predicted with a high degree of certainty, and others cannot. For many clinical situations, we do not have reliable statistical information about benefits and risks. Even where such information is available, it relates to populations rather than to the individual, so there is always some uncertainty about risks and benefits of health decisions for the individual. If consumers are to be actively involved and make informed health decisions, professionals need to be open about uncertainty surrounding benefits and risks.

Changing perceptions by 'framing' information

Emphasising one aspect of a health decision while leaving out another may change how people understand and perceive risks and benefits. This effect is called 'framing' of information. For example, health information can be framed as:

- **negative or positive** — for example, giving the chances of an operation failing (negative framing) versus the chances of it succeeding (positive framing)
- **loss or gain** — for example, emphasising the risks or disadvantages of not having a particular screening procedure (loss) versus emphasising the benefits or advantages of having the procedure (gain).

Understanding the difference between relative and absolute risk

Another factor that affects how people perceive risks and benefits is whether they are presented with **absolute** or **relative** risks. Using relative risks alone to compare different options can be misleading. For example, imagine that a drug is marketed as halving the risk of a heart attack (that is, it reduces the risk by 50%). These figures, which give the relative reduction in risk, make the drug sound highly effective. However, it is impossible to fully understand the meaning of this without knowing what the 50% reduction actually refers to. For example, if the initial chance of a person having a heart attack were only 1 in 2000 (0.05%), then reducing the risk by 50% would only mean bringing the chance down to 1 in 4000 (0.025%). Clearly, describing the effect of the drug in terms of the reduction in absolute risk does not sound nearly as dramatic or persuasive as using the relative risk. The figures for this imaginary drug can be summarised as follows:

- **relative risk** — the drug reduces the chance of a heart attack by 50%
- **absolute risk** — the drug reduces the chance of a heart attack from 0.05% (1 in 2000) to 0.025% (1 in 4000).

Thus, although the drug reduces the chance of a heart attack by 50% when compared to not using the drug, in real terms, the risk for the individual patient is reduced from 1 in 2000 if the drug is not taken, to 1 in 4000 if it is.

Putting benefits into perspective

Another way to look at benefits or risks is to ask how many people would need to have a treatment or test for one person to experience a particular benefit or harm. Using the example above:

- the number of people likely to have a heart attack *without* the drug is 1 in 2000 (0.05%)
- the number of people likely to have a heart attack *with* the drug is 1 in 4000 (0.025%)
- the difference between these figures is 0.025% (that is, 0.050% minus 0.025%).

Thus, for every 100 people treated with the drug, 0.025 benefit. From this figure, we can work out the 'number needed to treat' or NNT; that is, how many people would need to be treated for one person to benefit. The NNT is calculated as follows:

$$\text{Number needed to treat} = \frac{100}{(0.050 - 0.025)} = \frac{100}{(0.025)} = 4000$$

Another way to express this is to say that for every 4000 people who take the drug, one will benefit by not having a heart attack. The 'NNT' is thus an alternative way of presenting absolute data in an understandable way.

Decision aids

PURPOSE

Decision aids present health information for consumers and can take many forms, ranging from boards or booklets, to videos and computer-based programs. However, what makes decision aids different from conventional health information is that they discuss the risks and benefits of particular treatments or tests, often in a way that is tailored to be relevant to particular consumers. Decision aids are intended to help consumers:

- understand their choices for treatments or tests
- learn more about the benefits and risks associated with those choices
- determine the chances that particular benefits or risks will occur
- consider their personal values and circumstances relevant to the decision to be made.

Situations where decision aids are useful are those where there are various options, and different people might choose different courses of action. For example, in early breast cancer, some women will decide to have the breast removed, whereas others will decide to have only the lump removed. Both decisions are reasonable, and women have to weigh up the pros and cons of each of those options in working out the best decision for them. Using a decision aid can make weighing up the pros and cons

of each option easier. It can also help consumers to prepare for a consultation, so that the professional can spend less time giving facts and more time on discussing things that matter to the consumer.

BENEFITS

Decision aids have been shown to have a range of benefits. For example, they can:

- reduce consumers' uncertainty about which option to choose
- increase consumers' knowledge of their health problem, their options and what might happen if they choose particular options
- help consumers to have realistic expectations about their options
- improve agreement between the choices consumers make and the values that are important to them
- increase the participation of consumers without increasing their anxiety.

There is still work to be done to find out which types of decision aid work best with which decisions or with which types of consumers. Research is also needed to find out more about how acceptable decision aids are to different groups of consumers and professionals.

FINDING DECISION AIDS

Friendly Coaching for Tough Decisions is the title of a website developed by the Ottawa Health Research Institute in Canada.¹³ The site includes a list of the hundreds of decision aids developed worldwide that meet the criteria for inclusion on the site, listed alphabetically by topic. The titles make clear the relevant condition and the decision-making stage — for example, for 'bed-wetting', the list includes two decision aids, one for consumers deciding whether to see a professional about the problem, and another for those deciding whether to treat the condition.

The Screening and Test Evaluation Program (STEP) at the University of Sydney is looking at the use of decision aids for screening tests.¹⁴ For example, STEP is testing a decision aid for women aged around 40 years who are considering whether to start having mammography to screen for breast cancer.

13 <http://decisionaid.ohri.ca/index.html>

14 <http://www.health.usyd.edu.au/step/>

ASSESSING DECISION AIDS

The *International Patient Decision Aid Standards (IPDAS) Collaboration* brings together people from around the world who design, test, compile, provide or use consumer decision aids.¹⁵ The aim of the collaboration is to reach agreement about how to judge the quality of a decision aid. IPDAS has recently published a discussion document on setting standards for decision aids (O'Connor et al 2005).

What this means for healthcare consumers

As a healthcare consumer, you expect information about the risks and benefits of your options for treatment or tests that, as far as possible, is accurate, appropriate, unbiased and presented in a way that you can understand. You should let your healthcare professional know if you would like more information or need it explained in a different way. For example, if betting 'odds' make sense to you, you may prefer your healthcare professional to explain a risk in terms of the 'odds' that it will happen to you. Alternatively, if you are more of a visual person, you may prefer to look at a graph or a diagram showing a group of people, illustrating how many of them might expect to experience a particular side effect if they were given the treatment you are considering.

You will probably want to know if there is uncertainty about the risks and benefits. Often, your professional will not be able to tell you the exact chance of certain side effects occurring, or how bad they might be. This may be either because of variation between different people or because precise information about the particular risk or benefit is simply not available. Whatever the situation, you can always ask your professional's opinion about the risks and benefits in your particular case.

The *Tools for healthcare consumers* section of this principle provides information on how you can work with your healthcare professional to better understand the risks and benefits of health decisions that affect you.

What this means for healthcare professionals

In providing information to healthcare consumers, you can have different roles. For example, you can act:

- as a filter, determining which information is relevant to a particular healthcare consumer
- as a conduit, channelling information to the consumer
- as a reservoir from which the consumer can draw when needed.

Not surprisingly, consumers expect information about benefits and risks that is (as far as possible) accurate, unbiased, personally relevant to them and presented in a way that they can understand.

The way that you present information to consumers can influence how they perceive the risks and benefits, how well they understand the information and the extent to which they can use it to make informed decisions. Being aware of this situation can make it easier to tailor information to suit individual consumers, explain things in different ways and present information in different formats.

continued »

15 <http://ipdas.ohri.ca/index.html>

continued »

In many situations, detailed information about risks and benefits from high-quality research is not available, or may not apply to the current situation, so any advice you give is based on professional judgment. Sharing uncertainty and listening to consumers' concerns about risks and benefits is important and is also likely to improve your credibility. Although communication of these complex issues is difficult, it is necessary and should be as accurate, honest and sensitive as possible.

The *Tools for healthcare professionals* section of this principle provides strategies that you may find helpful in conveying risks and benefits.

EXAMPLES

The following studies and stories illustrate some aspects of the principle that information on risks and benefits needs to be comprehensive and accessible.

Studies

Mixed formats are most effective for communicating risk

A study from Wales (UK) looked at different ways of communicating risk in general practice. The study involved a training course for 39 general practitioners (GPs), who were divided into three groups and asked to present information about risk to people posing as healthcare consumers. The groups presented information either verbally (describing the risk), numerically, or by using a graph.

Graphs were the quickest and easiest way to present information; also, looking at a graph with the consumer helped the GP to build a relationship with the person, and allowed them to convey absolute and relative risks without having to explain these concepts. As there were some benefits in all the communication techniques used, the authors of the study suggest that using a range of presentation styles would probably be most effective for giving information about risks that is unbiased, easily understood and comprehensive. Having different presentation styles would allow GPs to be more flexible and tailor their communication to suit the needs of individual consumers. Generally, the GPs found the training program useful and felt that it improved their communication skills.

Source: Edwards et al 1999.

Healthcare consumers with early-stage breast cancer find decision aids helpful

Researchers in Canada reviewed five studies examining the use of decision aids to help women negotiate the difficult and complex decisions about early-stage breast cancer. For example, women need to decide whether to have the breast removed, or have just the lump removed and supplement this with breast radiation therapy. After surgery, they then have to decide whether to opt for chemotherapy, hormonal therapy, regional radiation therapy or no further treatment. Decision aids included a video, a multimedia tool, an audiotape plus workbook, a decision board and a CD-ROM.

The results showed that decision aids were helpful to women with early breast cancer — they improved the women's knowledge and made it easier for them to share decisions with their professionals.

Source: Levine and Whelan 2001.

Framing affects confidence in blood transfusions

Researchers in the United Kingdom looked at how consumers' confidence in the safety of blood transfusion is affected by the way in which information is presented. They asked about 250 adult students to imagine that they were about to undergo surgery and would require a blood transfusion. The researchers then gave the students additional information in different formats:

- **a gain** — one group was told that there are safety measures to prevent infection and that risks of infection are extremely small; they were also given information on risk of viral infections in terms of number of people who would *not* contract these infections
- **a loss** — a second group was not told about safety measures or the low risk of infection, and the information on risk of viral infections was presented in terms of number of people who *might* contract infections
- **a combination of these factors** — a third group was given the information on safety measures and low risk of infection (that is, gain), but were given the information on viral infection risk in terms of number of possible infections (that is, loss).

The study showed that people receiving the information framed as a gain were more confident of the safety of blood transfusion than either of the other two groups.

Source: Farrell et al 2001.

Difficulties in seeking ethical informed consent

An Australian study looked at current clinical practice when seeking informed consent from healthcare consumers about their participation in clinical trials. The study involved audiotaping of 59 consultations by 10 oncologists to assess shared decision making, the sequence in which information was given, the type and clarity of information, and the level of disclosure or coercion. The researchers found that many of the healthcare professionals did not address aspects of shared decision making, did not present information in a consistent sequence, made implicit statements favouring one option over another, and complied with only some aspects of a standard procedure for discussing clinical trials. The authors concluded that the results reflect inherent difficulties in seeking ethical informed consent, and the need for communication skills training for oncologists.

Source: Brown et al 2004.

Putting the principle into practice — tools for healthcare consumers

There are many different ways that information on risks and benefits can be presented. This section suggests questions that you might ask your healthcare professional to help you get information in a format that makes sense to you. It also discusses internet-based tools designed to:

- help in making health-related decisions
- evaluate either written health information or material from the internet.

GET BALANCED, ACCESSIBLE AND RELEVANT INFORMATION

Numbers — Your healthcare professional can explain numbers in different ways; for example, they might say:

- ‘25% of people having this treatment benefit from it’ (this is a ratio expressed as a percentage)

or

- ‘1 in 4 people having this treatment benefit from it’ and ‘If 4 people have this treatment then one person is likely to benefit’ (this is the same information as in the first bullet point, but given as a frequency rather than a percentage).

We know that people find it easier to understand and use information if it is given as a frequency.

Visual information — Explaining risks and benefits using a diagram, such as a graph or picture, can help to make them more real and put them into perspective. Also, having something visual that you and your professional can look at together can improve communication, making it easier for you to ask questions and check that you have understood the information you are given.

An example of this type of information is a diagram showing 1000 people, which the professional can colour in to show, for example, how many of those people might have a negative experience and how many a positive experience following a particular test or treatment. Looking at numbers in this way is particularly helpful in getting a balanced view, because you can see at the same time the number of people likely to experience benefits and risks (or neither) from the procedure.

Vivid and real information — It can be hard to imagine how a particular effect, whether it be a benefit or a risk, might feel to you. Hearing other people’s stories about their personal experience can help to make the information vivid and more real to you. You can find such information on the internet (see the *Find out more* section for this principle for some useful websites) and through consumer support groups, which you can locate via the internet, the phone book or a directory of self-help groups.

POSSIBLE QUESTIONS

Making sense of percentages

If a professional talks about numbers as percentages (for example, ‘There is a 25% chance of you having a particular side effect if you take a certain medication’) or as a comparison (for example, ‘This medication is half as likely as the last one you were taking to cause you problems with sleeping’), you might ask:

- If 100 people take that medication, how many of them would be likely to experience that side effect?
- Out of those 100 people, how many of them would be likely not to have the side effect?

Putting information into perspective

If you are finding it hard to put numbers into perspective, you might ask:

- Can you show me that information as a diagram or picture?
- Can you compare that to something I am more familiar with — like the risk of being in a car accident?

Gaining from the experience of others

If you have not experienced and cannot imagine a particular risk or benefit, you might ask:

- Where can I find out more about people who have had this treatment and experienced this side effect?

HELP WITH MAKING DECISIONS

The *Friendly Coaching for Tough Decisions* website mentioned above in the *Background* section of this principle has a tool called the *Ottawa Personal Decision Guide*.¹⁶ The guide, which can be printed or used online, is designed to be used with any health-related decision. The aim of the guide is to help you work out your needs in relation to a health decision, plan the next step and track progress.

16 <http://decisionaid.ohri.ca/decguide.html>

AN ONLINE TOOL FOR ASSESSING INFORMATION

If you are one of the many consumers who now uses the internet to find further information about your condition and the risks and benefits of treatment options, you may have found it difficult to work out which information you can trust. *DISCERN*¹⁷ is an online tool that can be used to assess printed information and material from the internet. It takes the form of a brief questionnaire that helps users to assess the quality of written information on treatment choices for a health problem. The Australian Government's *HealthInsite* website¹⁸ has a similar tool (see the link *How to assess health information online* on the site's home page).

OBTAINING A SECOND OPINION

If you feel that you would like to discuss your options with another healthcare professional, you can seek a second opinion. Doing so should not affect your relationship with the health professional you consulted initially.

EXERCISES FOR HEALTHCARE CONSUMERS

At the end of this section there are scenarios and questions designed to help healthcare consumers and healthcare professionals put into practice the tools and information given in this principle.

Putting the principle into practice — tools for healthcare professionals

This section presents some strategies you might find useful for discussing risks and benefits, and conveying that information in a way that will help consumers to understand it and use it to make informed decisions. Some of the main strategies are summarised here, and explained in more detail below:

- Where quantitative information is available, express it clearly. Consider using frequencies as well as percentages, and where you are giving relative figures, back these up with absolute risks or benefits.
- Make information more relevant by putting it in context, and make it more vivid by bringing in other people's experiences.

17 <http://www.discern.org.uk>

18 <http://www.healthinsite.gov.au/>

- Use multiple formats, to increase the likelihood that one of those formats will be clear to the particular consumer.
- Be frank and open about uncertainty, explaining clearly whether it is due to lack of data or to the difficulty of predicting who will experience a particular benefit or risk.
- Be sensitive and check that the consumer has understood the information you are giving them.

EXPRESS QUANTITATIVE INFORMATION CLEARLY AND AVOID BIAS

Where possible, avoid explaining risks and benefits only in descriptive terms, such as ‘very low risk’ or ‘high risk’, because these are subjective and what they mean to you may differ from what they mean to the consumer or even to another professional. Therefore, descriptive terms need to be qualified by giving a frequency.

Use frequencies (for example, 5 out of every 100 people) rather than (or as well as) percentages (for example, 5%). Percentages seem to be an abstract way of portraying risk, whereas the actual number of people who could be affected is more vivid. Also, when expressing risks as frequencies, consider using a consistent denominator; for example, compare a risk that is likely to affect 4 in 100 people with another is likely to affect 2 in 100 people (rather than 4 in 200).

To avoid bias, consider providing both absolute and relative data. For example, if you are discussing the risks of two treatments, express risks in terms such as ‘about 3 in 100 people may experience this side effect with drug A, compared to 6 in 100 with drug B’, rather than ‘treatment with drug B is twice as likely to cause this side effect’. Using absolute data allows the consumer to put into perspective the relative risk or comparison between different risks.

Another way to avoid bias and the effects of framing is to give information in terms of both positive and negative outcomes. For example, if you give the chance of survival from a surgical treatment as 98 in 100, you should also give the chance of dying as 2 in 100. Similarly, if you tell a consumer that a treatment is likely to cause a particular side effect in 4 out of 10 consumers, also explain that 6 out of 10 consumers are unlikely to experience that side effect.

PUT INFORMATION INTO CONTEXT

Giving the likelihood of a risk or a benefit as a number or percentage can be confusing for consumers, because numbers are difficult to put into context. It is often helpful to compare a particular risk with a familiar risk, such as the probability of winning the lottery or dying in a car crash. A list of such risks has been produced by the *British Medical Journal*,¹⁹ as part of an entire edition focusing on risk communication.²⁰

Another factor to think about when making risks relevant is the timeframe. For example, a risk of something occurring over the next 5 or 10 years may be relevant to a young person, whereas a lifetime risk may be more relevant to an elderly person.

MAKING INFORMATION REAL AND RELEVANT

In cases where the context is new to consumers, it may be useful to direct them towards resources that include stories of other people's personal experiences of a particular health problem. This can help consumers estimate the impact a decision may have on their lives.

Stories, narratives or personal accounts can help consumers to have a better idea of what the actual experience of a choice might be like. These methods can help in making sense of complex technical information, because they combine the richness of past experience with the logic of deliberate thought. Thus, they make the information easier to imagine and evaluate, and apparently also easier to remember. Particularly helpful are narratives tailored to the consumer's own health decision (the *Find out more* section of this principle includes a list of relevant websites). Such information is useful for illustrating situations and improving understanding, but consumers should not be making decisions based on anecdotal material.

USE MULTIPLE FORMATS TO INCREASE UNDERSTANDING

Using a range of presentation styles helps to reduce bias and increase consumers' understanding of the information. For example, you might supplement verbal descriptions with graphical representations and diagrams where these are available. A *Paling palette* is a chart showing (for example) 1000 people,

19 <http://bmj.bmjournals.com/cgi/content/full/327/7417/694/DC1>

20 27 September 2003 edition of *British Medical Journal*. Available online at <http://bmj.bmjournals.com/content/vol327/issue7417>

with some coloured in to show the number experiencing a particular effect. The chart is particularly useful in explaining risk because, at the same time, it shows both those experiencing an effect and those not experiencing it.

Consumers are more likely to use health information that is unbiased (for example, that includes both risks and benefits), well organised and interesting. *The Friendly Coaching for Tough Decisions* website mentioned above in the section on decision aids has an online tutorial for healthcare professionals, entitled *Training Practitioners in Decision Support*.²¹ This tutorial is a useful place to start if you would like to improve your skills in providing decision support to consumers.

BE OPEN AND FRANK ABOUT UNCERTAINTY

It is important not to give a false sense of certainty about risks and benefits if their exact likelihood is unknown. For such risks, you may find it better not to describe them as a numerical probability, but to be frank and to discuss the uncertainty about each option. Consumers may be more understanding if they realise that, although uncertainty sometimes reflects a lack of research or professional knowledge, it is often due to the difficulty of predicting outcomes for an individual, based on data that reflects the average responses found.

BE SENSITIVE AND CHECK FOR UNDERSTANDING

Emotions play a significant role in how consumers make decisions, so it is important to be sensitive, patient and respectful of the person.

Thinking about your own consultations, do you encourage consumers to give you feedback, to ensure that they have understood the information you are presenting and feel comfortable using it to make decisions? Do you ask during and at the end of the consultation ‘Is there anything else you would like to ask me?’ Do you ask them to repeat back to you instructions for how to take a new medication?

The tutorial on developing skills in providing decision support to consumers on the *Friendly Coaching for Tough Decisions* website is also useful for checking that consumers understand the information that you give them.²²

21 <http://decisionaid.ohri.ca/training.html>

22 <http://decisionaid.ohri.ca/training.html>

FIND MORE EVIDENCE-BASED INFORMATION

The *British Medical Journal* has published a workbook that introduces the concept of evidence-based medicine, and provides simple methods for finding and using evidence to answer clinical questions (Glasziou et al 2003). The workbook is practical and interactive. It aims to develop skills in:

- asking clinical questions (including those related to the benefits and risks of interventions)
- searching for answers
- using the answers, with healthcare consumers, to make clinical decisions.

EXERCISES FOR HEALTHCARE PROFESSIONALS

Below are scenarios and questions designed to help healthcare professionals and healthcare consumers put into practice the tools and information given in this principle.

Exercises for principle 5

Imagine you are in the position of the healthcare consumer or healthcare professional in the following scenarios, and think about how you might answer the questions below.

Scenario 1

Grace is a 55-year-old woman who has been on hormone replacement therapy (HRT) for the past two years. Recently, she has read in the newspaper that the risk of having a heart attack is doubled for women on HRT. Grace is worried about what she has read and is now wondering if she should stop taking her HRT. She has therefore made an appointment to see her GP.

Scenario 2

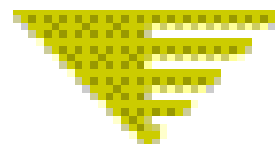
Chan is a first-year university student who has been diagnosed with depression. A GP at the university prescribed a course of antidepressants, and Chan has been on them for a couple of weeks. He has also been seeing one of the university's counsellors. The medication and the counselling are helping with the depression, but Chan is finding the side effects of the drugs difficult to deal with, and he is worried about becoming dependent on the medication. He would like to stop taking the medication, but a friend has told him that the depression could come back even more strongly if he does so.



How can I explain what's worrying me?

What information do I need to decide what to do?

Where could I get more information to help me weigh up the different options?



How can I explain the risks and benefits in a way that makes sense to this person?

What can I do to make the information clear and unbiased?

How can I check that they have as much information as they need, and what sources could I suggest if they want more information?

Find out more

CASE STUDIES

Part 2 of this toolkit has three case studies that illustrate some of the different ways of presenting health information.

RESOURCES

Audio information

Health Crossroads (<http://www.healthcrossroads.com>) is a website where consumers can listen to audio overviews for more than 70 decisions (referred to as crossroads). It covers conditions such as breast cancer, prostate cancer, coronary artery disease and back pain.

DECISION AIDS

Friendly coaching for tough decisions is a website developed by the Ottawa Health Research Institute in Canada. The site includes a list of the many decision aids developed worldwide that meet the criteria for inclusion on the site.

<http://decisionaid.ohri.ca/index.html>

The same site also has an online decision support tool:

<http://decisionaid.ohri.ca/decguide.html>

The *International Patient Decision Aid Standards (IPDAS) Collaboration* brings together people from around the world who design, test, compile, provide, or use consumer decision aids. The aim of the collaboration is to reach agreement about how to judge the quality of a decision aid. IPDAS has recently published a discussion document on setting standards for decision aids (O'Connor et al 2005).

<http://ipdas.ohri.ca/index.html>

The *Screening and Test Evaluation Program (STEP)* at the University of Sydney is looking at the use of decision aids for screening, at the accuracy and outcomes of screening and diagnostic tests, and at informed decision-making in such tests.

<http://www.health.usyd.edu.au/step/>

The *DISCERN* website, funded by the National Health Service of the United Kingdom, is an online resource for assessing health information available on the internet.

<http://www.discern.org.uk/>

The Australian Government's *HealthInsite* website has a page about assessing health information from the web, and many links to other assessment tools.

http://www.healthinsite.gov.au/topics/How_to_Assess_Health_Information_Online

Making decisions: Should I use hormone replacement therapy? (HRT) is a booklet produced by the NHMRC to help women who are thinking about using HRT to make their decision. The decision aid is designed for women who are about 50 years old, are considering HRT (tablets or patches containing oestrogen and progesterone) and have troublesome hot flushes. The booklet is part of a series of three publications that offer information and advice to health professionals and to consumers about the use of HRT.

<http://www.nhmrc.gov.au/publications/synopses/wh35syn.htm>

General health information

The website of the United Kingdom *National Electronic Library for Health* includes different levels of information for consumers on a range of health topics.

<http://www.nelh.nhs.uk>

Stories

The *Database of Individual Patient Experiences* is a website containing consumers' experiences.

<http://www.dipex.org>

BIBLIOGRAPHY

An asterisk * after a reference indicates that the study was a systematic review.

Barratt A, Trevena L, Davey HM and McCaffery K (2004). Use of decision aids to support informed choices about screening. *British Medical Journal* 329:507–510.

Bedell SE, Graboyes TB, Bedell E and Lown B (2004). Words that harm, words that heal. *Archives of Internal Medicine* 164:1365–1368.

Bessell TL, McDonald S, Silagy CA, Anderson JN, Hiller JE and Sansom LN (2002). Do internet interventions for consumers cause more harm than good? A systematic review. *Health Expectations* 5:28–37.*

Bottorff JL, Ratner PA, Johnson JL, Lovato CY and Joab SA (1998). Communicating cancer risk information: the challenges of uncertainty. *Patient Education and Counseling* 33:67–81.

Brown RF, Butow PN, Ellis P, Boyle F and Tattersall MH (2004). Seeking informed consent to cancer clinical trials: describing current practice. *Social Science and Medicine* 58:2445–2457.

Burkell J (2004). What are the chances? Evaluating risk and benefit information in consumer health materials. *Journal of the Medical Library Association* 92:200–208.

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

Clancy CM, Cebul RD and Williams SV (1988). Guiding individual decisions: a randomized, controlled trial of decision analysis. *The American Journal of Medicine* 84: 283–288.

Clerehan R, Buchbinder R and Moodie J (2005). A linguistic framework for assessing the quality of written patient information: its use in assessing methotrexate information for rheumatoid arthritis. *Health Education Research* 20:334–344.

Edwards A and Elwyn G (2001b). Understanding risk and lessons for clinical risk communication about treatment preferences. *Quality in Health Care* 10(Suppl):i9–i13.

Edwards A, Elwyn G and Gwyn R (1999). General practice registrar responses to the use of different risk communication tools in simulated consultations: a focus group study. *British Medical Journal* 319:749–752.

Edwards A, Elwyn G, Covey J, Matthews E and Pill R (2001). Presenting risk information — a review of the effects of ‘framing’ and other manipulations on patient outcomes. *Journal of Health Communication* 6:61–82.*

Edwards A, Elwyn G and Mulley AI (2002). Explaining risks: turning numerical data into meaningful pictures. *British Medical Journal* 324:827–830.

Edwards A, Unigwe S, Elwyn G and Hood K (2005). Personalised risk communication for informed decision making about entering screening programs (Cochrane Review).* <http://www.update-software.com/Abstracts/ab001865.htm>

Farrell K, Ferguson E, James V and Lowe KC (2001). Confidence in the safety of blood for transfusion: the effect of message framing. *Transfusion* 41:1335–1340.

Gigerenzer G and Edwards A (2003). Simple tools for understanding risks: from innumeracy to insight. *British Medical Journal* 327:741–744.

Glasziou P, Del Mar C and Salisbury J (2003). Evidence-Based Medicine Workbook: Finding and Applying the Best Research Evidence to Improve Patient Care. BMJ Books, London.

Hibbard JH and Peters E (2003). Supporting informed consumer healthcare decisions: data presentation approaches that facilitate the use of information in choice. *Annual Review of Public Health* 24:413–433.

Hoffrage U, Lindsey S, Hertwig R and Gigerenzer G (2000). Communicating statistical information. *Science* 290:2261–2262.

Johnson A, Stanford J and Tyndall J (2005). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home (Cochrane review).* <http://www.update-software.com/Abstracts/ab003716.htm>

Kuhberger A (1998). The influence of framing on risky decisions: a meta-analysis. *Organizational Behaviour and Human Decision Processes* 75:23–55.

Levine M and Whelan T (2001). Decision-making process — communicating risk/benefits: is there an ideal technique? *Journal of the National Cancer Institute Monographs* 30:143–145.

Llewellyn-Thomas HA (1997). Investigating patients' preferences for different treatment options. *Canadian Journal of Nursing Research* 29:45–64.

Lowe KC and Ferguson E (2003). Benefit and risk perceptions in transfusion medicine: blood and blood substitutes. *Journal of Internal Medicine* 253:498–507.

Mazur DJ and Hickam DH (1993). Patients' and physicians' interpretations of graphic data displays. *Medical Decision Making* 13:59–63.

Molenaar S, Sprangers MA, Rutgers EJ, Luiten EJ, Mulder J, Bossuyt PM, van Everdingen JJ, Oosterveld P and de Haes HC (2001). Decision support for patients with early-stage breast cancer: effects of an interactive breast cancer CDROM on treatment decision, satisfaction, and quality of life. *Journal of Clinical Oncology* 19:1676–1687.*

Morgan MW, Deber RB, Llewellyn-Thomas HA, Gladstone P, Cusimano RJ, O'Rourke K, Tomlinson G and Detsky AS (2000). Randomized, controlled trial of an interactive videodisc decision aid for patients with ischemic heart disease. *Journal of General Internal Medicine* 15:685–693.

Moxey A, O'Connell D, Mcgettigan P and Henry D (2003). Describing treatment effects to patients. How they are expressed makes a difference. *Journal of General Internal Medicine* 18:948–959.

O'Connor A (2001). Using patient decision aids to promote evidence-based decision making. *Evidence-Based Medicine* 6:100–102.

O'Connor AM, Fiset V, DeGrasse C, Graham ID, Evans W, Stacey D, Laupacis A, Tugwell P (1999). Decision aids for patients considering options affecting cancer outcomes: evidence of efficacy and policy implications. *Journal of the National Cancer Institute Monographs* 67–80.

O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M and Jones J. Decision aids for people facing health treatment or screening decisions (Update in Cochrane Database of Systematic Reviews, 2003, CD001431, PMID:12804407).* <http://www.update-software.com/Abstracts/ab001431.htm>

O'Connor AM, Legare F and Stacey D (2003). Risk communication in practice: the contribution of decision aids. *British Medical Journal* 327:736–740.

O'Connor A, Llewellyn-Thomas H and Stacey D (2005). Background document, International Patient Decision Aid Standards (IPDAS) Collaboration.

Rees CE, Ford JE and Sheard CE (2002). Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. *Patient Education and Counseling* 47:273–275.

Schapira MM, Nattinger AB and McHorney CA (2001). Frequency or probability? A qualitative study of risk communication formats used in healthcare. *Medical Decision Making* 21:459–467.

Sedgewick P and Hall A (2003). Teaching medical students and doctors how to communicate risk: combining the teaching of statistics with communication skills. *British Medical Journal* 327:694–695.

Stewart M, Brown JB, Boon H, Galajda J, Meredith L and Sangster M (1999). Evidence on patient–doctor communication. *Cancer Prevention and Control* 3:25–30.

Woloshin S, Schwartz LM and Ellner A (2003). Making sense of information on the web. *British Medical Journal* 327:695–696.

Wright P, Belt S and John C (2004). Helping people assess the health risks from lifestyle choices: comparing a computer decision aid with customized printed alternative. *Communication and Medicine* 1:183–192.

Case study 1:

Diagnostic intervention — prostate specific antigen (PSA) testing

Introduction

This case study looks in detail at a particular screening test — the prostate specific antigen (PSA) test for the early detection of prostate cancer in men with no symptoms suggestive of prostate disease. This section describes:

- what the test is, who it is aimed at and some of the factors that might influence the decision on whether to have a PSA test
- the current situation in communication of the PSA screening test (giving a general perspective and then highlighting some of the Australian resources that are available)
- published studies that illustrate how the five principles of good communication, outlined in Part 1 of this toolkit, apply to PSA testing in men
- hypothetical examples that illustrate how the principles apply in this situation
- relevant resources and references.

Although this case study focuses on the PSA test, it highlights many issues that apply to other screening tests, such as mammography, which is used to screen for breast cancer in women. The pros and cons of mammography have been looked at in a systematic review (Barratt et al 2002) and a recent editorial in the *British Medical Journal* (Taylor 2005). Also, an Australian group has developed easy-to-use estimates of the benefits and harms of two-yearly screening mammography for women in different age groups (Barratt et al 2005).

WHAT IS THE PSA TEST?

Normal cells in the prostate produce a protein known as '*prostate specific antigen*' (PSA). This protein can be detected using a blood test — the PSA test. When cancer is present in the prostate, the level of PSA in the blood rises, because the protein leaks out of the cancer cells. Thus, an increased level of PSA in blood can be used as an indicator of prostate cancer.

Although the PSA test is useful in deciding whether to have further tests, like all other tests, it is not foolproof — it cannot show with complete certainty that a person has or does not have prostate cancer. For every three men who have a higher than expected PSA level, only one is found to actually have prostate cancer when they have follow-up tests, such as a biopsy. On the other hand, some men who do have prostate cancer may have a PSA test result that is normal.

A positive result in a test (for example, a higher than expected level of PSA) when there is actually nothing wrong is referred to as a false positive. A negative test result (for example, a normal level of PSA) when the person actually has a disease is referred to as a false negative.

WHO IS THE PSA TEST AIMED AT?

Prostate cancer is the most common male cancer, and is found mainly in older men. Often, older men know someone of similar age with prostate cancer and feel that they would like to know for certain whether or not they have disease.

The PSA test has a relatively high rate of false positives. Even if prostate cancer is confirmed by additional tests, only a small proportion of prostate cancers are life threatening. The problem is that it is often difficult to distinguish the rare, highly dangerous cancers from the less harmful forms that are more common. Also, the treatment options available today can cause side effects (such as incontinence and impotence) that significantly reduce quality of life.

Most evidence-based guidelines recommend that men should be fully informed about the nature of prostate cancer, and the pros and cons of PSA testing, especially when there are no symptoms of prostate disease, so that they can make their own decision about whether to be tested or not.

Men who decide to have the PSA test and who would like to continue to be screened for the disease may choose to return for the test every 12 months. Those who choose not to have the test can review the decision annually with their GP.

WHAT FACTORS INFLUENCE THE DECISION TO HAVE A PSA TEST?

The decision about screening tests depends on each man's goals, fears and willingness to accept risk. The risks and benefits of the test are summarised below.

Choosing to have the PSA test

- Potential benefits of having the test:
 - the test will give an estimate of the risk of invasive prostate cancer, and may therefore decrease anxiety
 - a positive test may lead to the discovery of a cancer before it has spread
- Potential risks of having the test:
 - having the test may increase anxiety
 - a positive result may lead to investigations and treatment that carry some risk (such as impotence and incontinence).

Choosing not having the PSA test

- Potential benefits of not having the test:
 - avoid anxiety about the result
 - avoid risks associated with investigations and treatment.
- Potential risks of not having the test:
 - the consumer will lose the chance to prevent spread of the disease (assuming that the person has invasive prostate cancer, which is correctly diagnosed by the test).

If an individual wants to minimise his risk from prostate cancer and maximise his chance of living as long as possible, he is more likely to favour screening. If an individual wants to minimise his risk of complications resulting from possible treatment following a positive test (such as impotence and incontinence) and maximise his quality of life, he is less likely to favour screening.

To make such a decision, men need relevant information about:

- their personal risks from prostate cancer
- the risks and benefits of the PSA test
- the risks and benefits of subsequent tests and procedures in the event of a positive PSA result.

Healthcare professionals therefore need to have evidence-based information available in a form that can be easily understood by people of varying backgrounds and educational levels. Such presentations and follow up discussions need to take account of the man's preference for self-directed, practitioner-led or shared decision making.

Current situation in communication about the PSA screening test

GENERAL

We know that at present the PSA screening test may not be well communicated, with men not making informed choices and not feeling satisfied with the amount of information received or their level of involvement in the process. These points have been illustrated by a number of studies, some of which are described below. The situation is complicated by the fact that there are different opinions in the scientific literature about the risks and benefits of PSA testing, as highlighted by a recent article asking what healthcare professionals should be telling consumers about prostate cancer risk (Baade et al 2005).

Studies

Men often not aware of consequences of testing

A study in Australia involved interviews with 695 men. About 1 in 5 of the men had undergone a PSA test in the previous 12 months, with about two-thirds of these tests being a first PSA test. The researchers found that just under half of the men tested did not adequately understand the consequences of the test, and that men who had visited a doctor for lower urinary tract symptoms in the previous 12 months were about three times as likely to have had a PSA test than those who had not visited the doctor for this problem. They suggested that a better framework for PSA testing in general practice is needed, including the important elements of decision making, such as evidence, consumer preferences and the means to ensure counselling before testing.

Source: Pinnock et al 1998.

Healthcare professionals not discussing tests

In a study of about 160 healthcare professionals in the United States, most reported that they often do not discuss cancer screening tests with their patients. This was partly because of the practitioners' own beliefs and their intention to order the tests, and partly due to factors such as time constraints or a language barrier.

Source: Dunn et al 2001.

Men frequently unaware of being tested

Another study from the United States looked at almost 200 men who had undergone the PSA test. Almost a third (53 men) did not know that they had had the test. Of the 120 men who were aware of receiving the PSA test, less than half (56 men) could remember having a discussion about the risks and benefits.

Source: Federman 1999.

Men unaware of important facts about prostate cancer screening

Another study in the United States surveyed about 300 men in outpatient clinics, to determine their knowledge about, and experience of, screening. The researchers found that most men did not know key facts about the PSA test. African Americans appeared to be less knowledgeable than Caucasians, but factors such as education level and previous experience with prostate cancer screening could have contributed to the differences seen between the two groups.

Source: Chan et al 2003.

Testing without disclosure seen as unacceptable

A study in Australia looked at the degree to which men considered it appropriate for GPs to request a PSA test if the consumer was either aware that the test was being requested (test 'disclosed') or unaware (test 'undisclosed'). Using telephone surveys, 514 men were presented with two hypothetical scenarios — one in which the GP requested a PSA test along with other blood tests after disclosing the intention to include the PSA test, the other in which the GP did not tell the consumer that the PSA test was being requested. More than 90% of the men surveyed stated that 'disclosed' PSA was either 'appropriate' or 'very appropriate', whereas less than half rated 'undisclosed' testing as 'appropriate' or 'very appropriate'. The researchers concluded that including PSA screening in a battery of tests without informing the consumer is unacceptable.

Source: Gattellari and Ward 2005.

AUSTRALIAN SITUATION

In 2004, the Australian Prostate Cancer Collaboration (APCC), with support from the National Cancer Control Initiative (NCCI) held a workshop to look at what is happening now in Australia in PSA testing in general practice (Pinnock 2004). The workshop brought together about fifty people from around the country, including urologists, GPs, nurses, members of non-government cancer organisations, and healthcare consumers. Topics discussed included what is currently happening, what constitutes 'informed choice', and what could be done now to improve the situation regarding PSA testing in Australia. The workshop highlighted the need to improve communication of the pros and cons of the test, given the climate of anger, frustration and litigation arising from men feeling inadequately informed about the test.

However, many Australian resources are available to guide both healthcare consumers and professionals in making decisions about PSA testing, especially in men without symptoms of prostate disease. They include clinical practice guidelines from peak research organisations, decision aids produced by professional and consumer groups, and a variety of web-based resources. The *Resources* section at the end of this case study gives addresses, phone numbers and internet links for organisations, and lists the relevant resources they produce.

Applying the principles of good communication to decisions about PSA screening in men

This section explains what we know about the PSA screening test in relation to the five principles outlined in Part 1 of this toolkit, based on a search of the scientific literature.

PRINCIPLE 1:

GOOD COMMUNICATION BETWEEN HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS HAS MANY BENEFITS

A worthwhile outcome for PSA screening could be expressed as *men making an informed choice about whether or not to have a PSA test, and feeling satisfied with both the decision that they have taken and their level of involvement in the process*. An informed decision in this case would be one that incorporates information about:

- prostate cancer
- the risks and benefits of the test (including the risks and benefits of subsequent tests and procedures in the event of a positive PSA result)
- the person's preferences
- the healthcare professional's advice (to the extent that this is desired by the healthcare consumer).

Given the high rate of false positives of the PSA test, and the possible consequences of current treatment options in the event of a positive test result (which include *watchful waiting*), good communication about the test might lead to a lower uptake of the test than would be the case if men were not so well informed.

Studies

More detailed information reduced uptake of the PSA test

In a study of 205 men in the United States, half the group received scripted information that fully explained the advantages, disadvantages, risks and benefits of the PSA test, and the other half received a single sentence about the test. The men who received the scripted information were significantly less interested in undergoing PSA screening than the men in the control group.

Although the amount of information received was the factor that had the strongest effect on the men's decision, other factors also played a part. In both the test and the control groups, men who had a family history of prostate cancer were more likely to be interested in having the test. Also, the older the men were, the less likely they were to be interested in having PSA screening.

Source: Wolf et al 1996.

Presenting information by video or discussion (or both) reduced uptake of the PSA test

In another study in the United States, about 150 men were assigned to one of four groups providing information about PSA screening. The men received one of the following:

- usual care
- discussion about the risk and benefits of the test
- video on shared decision making
- video plus discussion.

Most of the men (97%) in the 'usual care' group requested the PSA test, whereas rates of uptake were lower in the other groups, and decreased as information provision improved (82% uptake in the discussion group, 60% in the video group and 50% in the video plus discussion group).

Source: Frosch et al 2001.

PRINCIPLE 2: HEALTHCARE CONSUMERS VARY IN HOW MUCH PARTICIPATION IN DECISION MAKING THEY DESIRE

Men vary in their desire for participation in decisions about PSA screening. Some want to take the decision themselves, some want the healthcare professional to take it for them, and some want a middle ground (that is, they want to share the decision to a greater or lesser extent with their practitioner).

This preference may change during the discussion, as information is exchanged and participants gain further understanding of the clinical and social issues involved.

Study

Wide variation in preferences for involvement in decision making

About 150 men were surveyed before and after a visit to a general practice. Before the visit, the men reported their preferences for deciding on the PSA screening test as follows:

- 19% wanted the practitioner to decide
- 37% preferred a shared approach
- 30% wanted slightly greater control themselves
- 14% wanted complete control.

The preferences were similar after the visit, although the percentage of men who wanted the practitioner to decide had fallen to 9%.

After the visit, almost 25% of the men said that they had taken more control of the decision-making process than they desired, and about one-third of the men who wanted a shared approach actually made the decision themselves.

Reference: Woolf et al 2005.

PRINCIPLE 3: GOOD COMMUNICATION DEPENDS ON RECOGNISING AND MEETING THE NEEDS OF HEALTHCARE CONSUMERS

Various studies have compared knowledge about prostate cancer and the PSA test in men from different educational and cultural backgrounds, and preferences for information presentation. The results suggest that healthcare professionals need to take into account factors such as level of education and cultural preferences when giving information about the PSA test.

Studies

Cultural differences affect preferences for information presentation

A study in the United States looked at how African Americans, Hispanics and Caucasians wanted information about the PSA test. Twenty men aged 50 or older participated in one of four focus groups to discuss their views on the content and design of culturally sensitive brochures promoting informed decision making about prostate cancer screening.

The study found that participants preferred information to be presented in ways appropriate to their cultural background. For example, the Caucasian men likened the size of the prostate to a walnut, whereas Hispanic men likened it to a small lime. Hispanics emphasised how advanced prostate cancer can be symptomatic, whereas Caucasians focused on the fact that early prostate cancer can be asymptomatic. African Americans wanted risk information specific to them and the advantages and disadvantages of the PSA test, whereas Hispanics did not want such information.

The authors suggest that the differences seen in the study reflect cultural differences in attitudes towards the physician–patient relationship, preventive healthcare and informed decision making

Source: Chan et al 2003.

Differences in knowledge of test linked to level of education

Another study in the United States surveyed 160 men aged between 45 and 70 years before a general consultation, to see what they knew about prostate cancer and PSA screening. Many of the healthcare consumers lacked knowledge about prostate cancer and early detection. College graduates were more knowledgeable than the group as a whole, but most of the other men could not identify the main advantages and disadvantages of having the test. The authors note that lack of knowledge is a barrier to making an informed decision about whether to have the test.

Source: O'Dell et al 1999.

PRINCIPLE 4: PERCEPTIONS OF RISKS AND BENEFITS ARE COMPLEX, AND HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS MAY HAVE DIFFERENT PRIORITIES

There are many factors that affect how men make the decision whether to undergo PSA testing. Men may have certain beliefs that do not always agree with the evidence presented by their healthcare professional; for example, their fear of cancer may outweigh any fear of impotence. They may also have worries about their quality of life, which may affect their willingness to undergo testing. The attitudes of their family will also affect their decision.

Studies

Existing beliefs affect decision on PSA test

In a study in the United States, 40 men aged 40–65 were given written surveys and interviews before and after a PSA counselling session. Thirty of the men had been PSA tested in the past. Most of the men (about 93%) said that the counselling was unfavourable towards PSA; nevertheless, three-quarters of the men intended to be tested. In particular, 97% of the men who had been tested before said that they intended to be tested in future. Many of the participants cited underlying beliefs as the reason for discounting the counselling information. Most of these beliefs were credible on a personal level (for example, fear of cancer and anecdotal information from friends or celebrities).

Some of the responses from the men (which illustrate their views, not the situation accepted by the medical community) were:

- 'I don't think MOST people should have a PSA ... I still want it because bad things happen to me.'
- 'All that doesn't matter. The real issue is whether you want to have cancer. If you do, by all means listen to statistics. If you don't, get the test!'
- 'I'd be too afraid of cancer ... I could never look at the numbers and decide like I do at work.'

If widespread, such beliefs may render clinician counselling and decision support methods less effective. Eliciting patient beliefs prior to counselling may improve the shared decision-making process.

Source: Farrell et al 2002.

continued »

continued »

Men and their partners may differ in their attitudes to the PSA test

In a survey of 10 married couples in the United States, husbands and wives were interviewed separately about the risks of the PSA test. Men attached greater importance to potential consequences of a positive test (that is, incontinence and/or impotence). Wives attached greater importance to length of life — 7 out of 10 husbands preferred no screening, whereas only 1 out of 10 wives preferred no screening. If couples are making decisions together, these differences need to be considered.

Source: Volk et al 1997.

Urinary tract infection strongest factor in decision to have PSA test

A study in Australia surveyed 736 men aged 40 and over with no history of prostate cancer to investigate factors affecting the decision over whether to have a PSA test. Strongly associated with a decision to have the test was a previous visit to a doctor for treatment of a lower urinary tract infection, whereas beliefs, occupation and education were not found to be linked to the decision. About three-quarters of the men surveyed believed that prostate cancer could be cured if detected early. Only 15% believed they were unlikely to suffer from prostate cancer.

Source: Weller et al 1998.

PRINCIPLE 5: INFORMATION ON RISKS AND BENEFITS NEEDS TO BE COMPREHENSIVE AND ACCESSIBLE

In discussing the PSA test, professionals need to provide consumers with information on the risks and benefits of the test in a form that is comprehensive and accessible.

Several studies have directly compared different methods of providing information, using outcomes such as knowledge (before and after), satisfaction with the decision-making process and level of uptake of the PSA test. Not enough information is available to say which type of intervention is best overall, but information videos scored well in several studies.

Study

Better uptake of video information than of website

A study in the United States looked at the effect of different types of information on consumers making decisions about prostate cancer screening. More than 200 men attending an examination at a clinic were randomly assigned to either access a website at home or view a videotape in the clinic before deciding whether or not to be screened. The two information sources contained similar material and both took about 25–30 minutes to view. The researchers found that almost all the men in the videotape group actually looked at the tape, but only about half of those in the website group viewed the site at home. By the end of the study, the men in the video group knew more about the PSA test and were more likely to prefer to watch and wait (rather than have the test) than those in the website group.

Source: Frosch et al 2003.

DECIDE

When the information has been shared between professional and consumer in the way described above, the next stage will be to decide what to do next. Options include:

- do nothing
- take the test
- think it over
- get more information
- consider the information provided
- talk to partner, family, etc.

As explained above, men will vary in their preferences and priorities, in how they see the risks and benefits of having or not having the test, and in how much they wish to be involved in the decisions. Each of these factors may change during a consultation, over time or as the man receives more information. At this decision-making stage, the professional needs to be sensitive to the man's needs and help to bring the process to a conclusion in the most appropriate way.

Examples

The following examples apply the principles to hypothetical situations in which men are deciding whether to have a PSA test.

BRUCE'S SITUATION

Bruce is a healthy 70-year-old man. There is no-one in his family who has had prostate cancer. He enjoys an active life and has recently remarried. His sexual relationship is important to his quality of life.

If Bruce had the PSA test and it was abnormal, and follow-up investigations revealed a small tumour, he would probably ignore it rather than seek active treatment. He is not concerned about the risk of having a more advanced, larger, cancer.

Bruce's decision

Benefits
Have PSA test



Risks
Don't have PSA test

Deciding factors:

- Age
- Lack of family history of prostate cancer
- Active sex life

Bruce decides that, in his case, the risks associated with having a positive PSA test outweigh the benefits, and he chooses not to have the test.

PETER'S SITUATION

Peter is a healthy 55-year-old man. Because his father has prostate cancer, Peter is very concerned about the disease. After discussions with his wife, he feels it is most important to him to minimise his risk from the disease. If prostate cancer was found, he would probably have it actively treated, even if it was not fast growing.

Peter's decision

Benefits
Have PSA test



Risks
Don't have PSA test

Deciding factors:

- Age
- Family history of prostate cancer
- Own preference to minimise risk of disease
- Partner's preference

Peter decides that, in his case, the benefits associated with having a PSA test outweigh the risks associated with a positive test, and he chooses to have the test.

JOHN'S SITUATION

John is a healthy 60-year-old man. He has no relatives with prostate cancer. John is unsure of which way to go. He has no reason to suspect he is at risk, but after a couple of his friends were diagnosed with prostate cancer, he feels that he wants to have the test to be sure. John wants a test to put his mind at rest. However, if the test is negative, he will not bother to have it checked again.

John's decision

Benefits
Have PSA test



Risks
Don't have PSA test

Deciding factors:

- Age
- Concerns due to experience of friends having prostate cancer

John decides that, in his case, the benefits associated with having a PSA test outweigh the risks associated with a positive test, and he chooses to have the test.

Resources

Australian Prostate Cancer Collaboration

The Australian Prostate Cancer Collaboration, which involves healthcare consumers and healthcare professionals, has produced many resources, including a decision 'show' card to help general practitioners and consumers make informed choices about testing, and a consumer version of the NHMRC guideline on localised prostate cancer.

Address: PO Box 201, Spring Hill, Queensland 4006

Phone: 07 3258 2257

Website: <http://www.auspcc.org.au>

Publications:

The Early Detection of Prostate Cancer in General Practice
(‘show card’ for use by GPs and consumers)

Download: http://www.ncci.org.au/services/PSA_decision_card.pdf

Order: Cancer Council Helpline 13 11 20

Localised Prostate Cancer: A Guide for Men and Their Families

Download: http://www.cancer.org.au/documents/prostate_cancer_guide.pdf

Order: Cancer Council Helpline 13 11 20

The Cancer Council Australia

The latest version of the Cancer Council of Australia's statement on prostate cancer screening is available from the council or online through the council's website.

Address: GPO Box 4708, Sydney, NSW 2001

Phone: 02 9036 3100

Website: <http://www.cancer.org.au>

Publication

Prostate Cancer Screening Position Statement — http://www.cancer.org.au/documents/Pos_State_Prostate_cancer_screening_MAY2005.pdf

Lions Australian Prostate Cancer Website

This site has been developed by the education committee of the Australian Prostate Cancer Collaboration with funding from the Lions International Clubs of Australia.

Website: <http://www.prostatehealth.org.au>

Publications:

Should I be tested? (consumer's decision aid) — http://www.prostatehealth.org.au/v3/html/sheet_1.htm

Other information sheets: <http://www.prostatehealth.org.au/v3/index.htm>

Support groups: http://www.prostatehealth.org.au/perl/repaf?event_id=23

National Breast Cancer Council

The National Breast Cancer Centre (NBCC) was established in 1995 by the Australian Government in response to community concerns about the human cost of breast cancer. In 1999, it expanded to also cover ovarian cancer. To improve the awareness and capacity of healthcare professionals to communicate effectively with women with cancer, the NBCC sponsors communication skills workshops for professionals.

Address: Locked Bag 16, Camperdown NSW 1450

Phone: 02 9036 3030

Website: <http://www.nbcc.org.au/>

National Cancer Control Initiative

The National Cancer Control Initiative is an expert reference body that provides advice, identifies promising initiatives and makes recommendations to government and other groups about the prevention, detection, treatment and palliation of cancer.

Address: 1 Rathdowne Street, Carlton, Victoria 3053

Phone: 03 9635 5108

Website: <http://www.ncci.org.au>

Publication:

Developing National Strategies for Improving the use of the Prostate Specific Antigen Test in the Australian Community (a current project) — <http://www.ncci.org.au/projects/prostate/psa.htm>

National Health and Medical Research Council guidelines

The guidelines for the PSA test produced by the NHMRC are evidence based; that is, they reflect what we know about the test from the scientific literature. In common with guidelines produced by other countries, the NHMRC guidelines do not recommend that all men should be offered the test (an approach known as ‘*population screening*’), because at present there are no scientific studies showing that prostate cancer screening programs save lives.

Address: Office of NHMRC, GPO Box 1421,
Canberra, ACT 2601

Phone: 13 000 64672 (publications); 02 6217 9000 (general inquiries)

Website: <http://www.nhmrc.gov.au>

Publications:

Clinical Practice Guidelines: Evidence-based Information and Recommendations for the Management of Localised Prostate Cancer (2002) — <http://www.nhmrc.gov.au/publications/synopses/cp88syn.htm>

Clinical Practice Guidelines: The Management of Uncomplicated Lower Urinary Tract Symptoms in Men (2000) — <http://www.nhmrc.gov.au/publications/synopses/cp42syn.htm>

Is it my Prostate Doc? — A Guide for General Practitioners (1997) — <http://www.nhmrc.gov.au/publications/synopses/cp43syn.htm>

Prostate Cancer Foundation of Australia

The Prostate Cancer Foundation of Australia website (sponsored by an insurance company, a bank, an oncology company and a pharmaceutical company) includes pages of general information, articles and links.

Address: PO Box 1332, Lane Cove, NSW 1595

Phone: 02 9418 7942

Website: <http://www.prostate.org.au>

Publications:

Prostate Specific Antigen (PSA) and Informed Consent for PSA Testing in Men Without Urinary Symptoms, by Dr John Rogers — <http://www.prostate.org.au/psa2.htm>

References

An asterisk * after a reference indicates that the study was a systematic review.

Anderson D (1977). Shared decision-making programs: descriptive analysis of experience with shared decision-making programs in VA. A systematic review: assessing the effectiveness of shared decision-making programs for prostate care. *Technology Assessment Program Report No. 6*. Management Decision and Research Centre, Health Services Research and Development Services, Veterans Health Administration, United States.*

Baade PD, Steginga SK, Pinnock C and Aitken JF (2005). Communicating prostate cancer risk: What should we be telling our patients? *Medical Journal of Australia* 182:379–381. http://www.mja.com.au/public/issues/182_09_020505/baa10588_fm.html

Baade P, Steginga S et al (in press). Telling the story about prostate cancer risk: a challenge in risk communication. *Medical Journal of Australia*.

Barratt AL (2005). *Cancer Screening: Is it Worth it?* Health Matters, The Pulse, Australian Broadcasting Company. <http://www.abc.net.au/health/thepulse/s1438910.htm>

Barratt AL, Irwig LM, Glasziou PP, Salkeld GP and Houssami N (2002). Benefits, harms and costs of screening mammography in women 70 years and over: a systematic review. *Medical Journal of Australia* 176:266–271.* http://www.mja.com.au/public/issues/176_06_180302/bar10315.html

Barratt A, Howard K, Irwig L, Salkeld G and Houssami N (2005). Model of outcomes of screening mammography: information to support informed choices. *British Medical Journal* 330:936–940. <http://bmj.bmjournals.com/cgi/content/full/330/7497/936>

Chan EC, Haynes MC, O'Donnell FT, Bachino C and Vernon SW (2003a). Cultural sensitivity and informed decision making about prostate cancer screening. *Journal of Community Health* 28:393–405.

Chan EC, Vernon SW, O'Donnell FT, Ahn C, Greisinger A and Aga DW (2003b). Informed consent for cancer screening with prostate-specific antigen: how well are men getting the message? *American Journal of Public Health* 93:779–785.

Dudley T and Nagle J (2005). Enhancing your practice: How to explain risk to patients: Screening for prostate cancer. *Patient Care*. <http://www.patientcareonline.com/patcare/article/articleDetail.jsp?id=165978>

Dunn AS, Shridharani KV, Lou W, Bernstein J and Horowitz CR (2001). Physician–patient discussions of controversial cancer screening tests. *American Journal of Preventive Medicine* 20:130–134.

Farrell MH, Murphy MA and Schneider CE (2002). How underlying patient beliefs can affect physician–patient communication about prostate-specific antigen testing. *Effective Clinical Practice* 5:120–129.

Federman DG, Goyal S, Kamina A, Peduzzi P and Concato J (1999). Informed consent for PSA screening: does it happen? *Effective Clinical Practice* 2:152–157.

Frosch DL, Kaplan RM and Felitti V (2001). Evaluation of two methods to facilitate shared decision making for men considering the prostate-specific antigen test. *Journal of General Internal Medicine* 16:391–398.

Frosch DL, Kaplan RM and Felitti VJ (2003). A randomized controlled trial comparing internet and video to facilitate patient education for men considering the prostate specific antigen test. *Journal of General Internal Medicine* 18:781–787.

Gattellari M and Ward JE (2003). Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomized controlled trial. *Journal of Medical Screening* 10:27–39.

Gattellari M and Ward JE (2005). Men’s reactions to disclosed and undisclosed opportunistic PSA screening for prostate cancer. *Medical Journal of Australia* 182:386–389. http://www.mja.com.au/public/issues/182_08_180405/gat10770_fm.html

O’Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M and Jones J. Decision aids for people facing health treatment or screening decisions (Update in Cochrane Database of Systematic Reviews, 2003, CD001431, PMID:12804407).* <http://www.update-software.com/Abstracts/ab001431.htm>

O'Dell KJ, Volk RJ, Cass AR and Spann SJ (1999). Screening for prostate cancer with the prostate-specific antigen test: are patients making informed decisions? *Journal of Family Practice* 48:682–688.

Pinnock C (2004). PSA testing in general practice: Can we do more now? *Medical Journal of Australia* 180:379–381. http://www.mja.com.au/public/issues/180_08_190404/pin10813_fm.html

Pinnock C, Weller D and Marshall V (1998). Self-reported prevalence of prostate specific antigen (PSA) testing in South Australia: a community study. *Medical Journal of Australia* 169:25–28. <http://www.mja.com.au/public/issues/jul6/pinnock/pinnock.html>

Schapira MM and VanRuiswyk J (2000). The effect of an illustrated pamphlet decision-aid on the use of prostate cancer screening tests. *Journal of Family Practice* 49:418–424.

Slevin TJ, Donnelly N, Clarkson JP, English DR and Ward JE (1999). Prostate cancer testing: behaviour, motivation and attitudes among Western Australian men. *Medical Journal of Australia* 171:185–188.

Steginga SK (2003). How patients make decisions: the role of lay beliefs about health. Providing Informed Choice for Prostate Cancer Testing in General Practice, Australian Prostate Cancer Collaboration, Melbourne.

Steginga SK, Occhipinti S, Gardiner RA, Yaxley J and Heathcote P (2002). Making decisions about treatment for localized prostate cancer. *BJU International* 89(3):255–260.

Taylor P (2005). Making decisions about mammography. *British Medical Journal* 330:915–916. <http://bmj.bmjournals.com/cgi/content/extract/330/7497/915>

Volk RJ, Cantor SB, Spann SJ, Cass AR, Cardenas MP and Warren MM (1997). Preferences of husbands and wives for prostate cancer screening. *Archives of Family Medicine* 6:72–76.

Volk RJ, Spann SJ, Cass AR and Hawley ST (2003). Patient education for informed decision making about prostate cancer screening: a randomized controlled trial with 1-year follow up. *Annals of Family Medicine* 1:22–28.

Ward JE, Hughes A-M, Hirst GHL and Winchester L (1997). Men's estimates of prostate cancer risk and self-reported rates of screening. *Medical Journal of Australia* 167:250–253. <http://www.mja.com.au/public/issues/sep1/ward/ward.html>

Weller D, Pinnock C, Silagy C, Hiller JE and Marshall VR (1998). Prostate cancer testing in SA men: influence of sociodemographic factors, health beliefs and LUTS. *Australian and New Zealand Journal of Public Health* 22:400–402.

Weller D, May F, Rowett D, Esterman A, Pinnock C, Nicholson S, Doust J and Silagy C (2003). Promoting better use of the PSA test in general practice: randomized controlled trial of educational strategies based on outreach visits and mailout. *Family Practice* 20(6):655–661.

Wolf AM, Nasser JF, Wolf AM and Schorling JB (1996). The impact of informed consent on patient interest in prostate-specific antigen screening. *Archives of Internal Medicine* 156:1333–1336.

Woolf SH, Krist AH, Johnson RE and Stenborg PS (2005). Unwanted control: how patients in the primary care setting decide about screening for prostate cancer. *Patient Education and Counseling* 56:116–124.

Case study 2:

Procedural intervention — coronary angioplasty for heart disease

Introduction

This case study looks in detail at a particular procedural intervention — coronary angioplasty for heart disease.

This section describes:

- what the procedure is, the kind of situation in which it might be offered, and some of the factors that might influence the decision on whether to choose this option
- the current situation in communication of the procedure
- published studies that illustrate how some of the principles of good communication, outlined in Part 1 of this toolkit, apply to coronary angioplasty (note: for some of the principles, no relevant studies were found)
- a hypothetical example that illustrates how the principles apply in this situation
- relevant references.

Although this case study focuses on coronary angioplasty, it highlights many issues that apply to other medical procedures.

WHAT IS CORONARY ANGIOPLASTY?

Coronary artery disease is caused by the buildup of fatty deposits (referred to as '*plaque*') inside the arteries that carry blood to the heart. This reduces or blocks the flow of blood to the heart muscle. Narrowing of one or more of the coronary arteries that supply the heart can lead to angina, the symptoms of which include pain or discomfort in the chest, arms, back, neck or jaw. This pain can be a tightness, severe crushing sensation, or even numbness.

For people with angina that does not improve with medication, coronary angioplasty and bypass surgery are two effective treatments. In coronary angioplasty, a thin tube with a balloon attached to the end is threaded through the body to the blocked coronary artery. The balloon is then inflated to open up the vessel and let blood through. In a bypass operation, a piece of artery or vein is taken from some other part of the body and used to 'bypass' the blocked section of the coronary artery. Compared to bypass surgery, coronary angioplasty is less invasive, less expensive, faster to perform, and the patient is usually able to return home the next day.

Current situation in communication about coronary angioplasty

Depending on their background, experience and knowledge, consumers may find it hard to fully understand the benefits and risks of coronary angioplasty, compared to not having a procedure at all, or to having an alternative procedure, such as a bypass. They may also underestimate, or sometimes overestimate, the possible benefits that can be derived from making changes such as stopping smoking, eating a healthier diet and getting more exercise.

Study

Many healthcare consumers misunderstand the risks and benefits of coronary angioplasty

In a study in Northern Ireland, researchers looked at what 150 consumers understood to be the benefits of coronary angioplasty, and the extent to which they were able to make informed choices about their treatments. About 80% of the consumers greatly overrated the capacity of angioplasty to control their disease and most of these people also underestimated the benefits of a healthy lifestyle (for example, using diet to reduce blood cholesterol, not smoking and taking more exercise).

Source: Kee et al 1997.

Applying the principles of good communication to decisions about coronary angioplasty

A worthwhile outcome for a decision about coronary angioplasty could be expressed as *healthcare consumers making an informed choice about whether or not to have the procedure, and feeling satisfied with both the decision that they have taken and their level of involvement in the process*. An informed decision in this case would be one that incorporates information about:

- coronary heart disease
- the risks and benefits of the procedure
- the risks and benefits of alternatives (such as doing nothing, making lifestyle changes or having a bypass operation)
- the person's preferences
- the healthcare professional's advice (to the extent that this is desired by the person).

PRINCIPLE 1:

GOOD COMMUNICATION BETWEEN HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS HAS MANY BENEFITS

Good communication of what is involved in coronary angioplasty can make a difference both to healthcare consumers and to their families, as shown by the study below.

Study

Education and counselling can improve quality of life after coronary angioplasty

Researchers in Australia looked at the effect of an education and counselling program on people undergoing coronary angioplasty. Eighty consumers and their partners were enrolled in the study; 40 underwent the education and counselling program, and the other 40 served as controls. All participants received conventional ward care and education normally offered to consumers undergoing the procedure. Knowledge of risk factors, psychological status and quality of life/coping status were assessed before the procedure, and at 4 and 11 months after it.

At 4 months, the consumers in the education and counselling program group were more knowledgeable about risk factors and were less anxious than those in the control group. At 11 months, spouses of consumers in the program group scored better on quality of life and coping status than those in the control group. The researchers concluded that education and counselling before coronary angioplasty can improve knowledge in consumers and quality of life in spouses.

Source: Tooth et al 1997.

PRINCIPLE 2: HEALTHCARE CONSUMERS VARY IN HOW MUCH PARTICIPATION IN DECISION MAKING THEY DESIRE

Healthcare consumers vary in their desire for participation in decisions about coronary angioplasty. Some want to take the decision themselves, some want the healthcare professional to take it for them, and others want a middle ground (that is, they want to share the decision to a greater or lesser extent with their professional).

This preference may change during the discussion, as information is exchanged and participants gain further understanding of the clinical and social issues involved. The studies below indicate that professionals need to be explicit in giving consumers the chance to participate in decisions if they wish; they also show the possible negative impact of lack of control in decision making.

Studies

Consumers and professionals vary in preferences for shared decision making

A study in the United States explored the extent to which consumers and professionals desired consumer participation in medical decision making by surveying 92 consumers with coronary artery disease and 50 professionals involved in treating such consumers. The researchers found that the professionals preferred to share decision making more often than did the consumers. When faced with clinical scenarios requiring a decision to be made between coronary angioplasty and bypass surgery, both consumers and professionals tended to defer to one another to make the decision. The authors concluded that professionals need to ensure that their dialogue with consumers reflects important information about the different treatment options and need to acknowledge preferences to achieve satisfactory health outcomes and patient satisfaction.

Source: BeLue et al 2004.

Lack of control in decision making can lead to negative perceptions of treatment

A study in the United States used focus groups to collect information on consumers' experience of coronary angioplasty. Participants were 45 people (26 male, 19 female) who had undergone the procedure 3–18 months before the interviews. Various themes emerged from the interviews, the most frequent positive theme being supportive hospital care before, during and after the procedure. Other positive themes were contentment with comfort measures and trust in medical competence. Frustration with lack of control in decision making was one of the main negative themes, together with anger over unmet needs for comfort or support, and feeling dehumanised. Overall, most participants described very positive experiences, but many expressed bitter dissatisfaction with certain aspects of their care.

Source: Gulanick et al 1997.

Many consumers misunderstand the risks and benefits of coronary angioplasty

In a study in Northern Ireland, researchers looked at what 150 consumers understood to be the benefits of coronary angioplasty, and the extent to which they were able to make informed choices about their treatments. Although most of the consumers asked the consultant questions, about 70% of the participants thought that they had contributed negligibly or not at all to the treatment decision.

Source: Kee et al 1997.

Example

The following example applies the principles of good communication to a hypothetical situation in which someone is deciding whether to opt for coronary angioplasty. Since there are few publications about communication of this procedure, the example is based partly on evidence and partly on the application of knowledge gained from communication of other medical conditions.

The example describes the situation of a healthcare consumer who requires treatment for a heart condition, and is told from the consumer's point of view.

The first consultation

Richard is a 47-year-old high-school teacher in rural Western Australia. Although he drank and smoked heavily in his youth, in recent years he has cut down to five cigarettes a day, drinks only moderately and gets plenty of exercise coaching his young son's soccer team. A few months ago, Richard went to see the town's only GP after experiencing tightness in his chest. The GP diagnosed angina and put Richard on medication; he mentioned that some people do not improve with drugs and need other treatment, but he did not go into details. At the time, Richard was feeling too concerned about the diagnosis to pay much attention, and didn't think to ask any further questions.

Getting more information

The chest pains continue in spite of the medication, so Richard makes an appointment to go back to see the GP, but first he decides to find out more about his options. He knows that his uncle had a coronary bypass a few years ago and made a good recovery, but Richard is concerned about the time he would have to take off work if he needed to have such a major operation. He searches the internet and finds that a procedure called coronary angioplasty (which he had not heard of before) is an alternative to

bypass surgery for some people with angina. He searches further and finds a brochure about coronary angioplasty.²³ The brochure is clearly written and Richard feels confident that he has the facts he needs. However, he does not find his GP easy to talk to, and is worried about whether he will be able to discuss the options fully with him. He decides to see if he can find any websites that have information on talking to a healthcare professional about angina. His searching brings up a site from the United States that has a page entitled *You and your physician*.²⁴ It includes a list of suggestions that can be summarised as:

- **Prepare in advance** — Prepare a concise description of your symptoms to share with your physician and make a list of brief, specific questions.
- **Research** — Look for resources, learn appropriate medical terminology and a bit about standard treatments, so that you are more equipped to ask questions.
- **Bring a support person along** — It can help to have a second set of ears, especially when you are feeling anxious. It can also be helpful to tape record the conversation to review later — you might bring a recorder and ask if your health provider is comfortable with your taping the session to help you remember.
- **Speak up** — Mention your most important concerns at the beginning of the visit. Ask the doctor to explain what you don't understand.
- **Repeat** — It can be helpful to summarise briefly the key points from your discussion.
- **Make a follow-up plan** — Be clear what the next step is.

Richard decides to follow this advice. He contacts his friend Joe and asks him to come along to the consultation. He also contacts the GP surgery to ask for a double appointment (so that he can have more time with the GP) and to let them know that he will be bringing a friend to his appointment. Finally, he prepares a list of questions about the treatment options.

The second consultation

The consultation goes well, better than Richard had expected. Joe comes with him and takes some notes on what the GP says, which means that Richard can relax and not worry about making sure

23 Coronary Angioplasty and Coronary Stent Implantation, from the National Heart Foundation; <http://www.heartfoundation.com.au>

24 <http://www.angioplasty.org/nv/youandyourmd.html>

he has taken in all the information. Also, he finds that the list of prepared questions helps him to remember to mention everything he is concerned about.

The GP recommends coronary angioplasty, but Richard feels that he needs more time to think about it, and says so. He realises that although he has the facts about angioplasty, he doesn't know anyone who has had this procedure, so he would like to find out more about the actual experience. Also, he decides that he would like to first try improving his diet and giving up smoking to see if this makes a difference, before opting for the angioplasty.

The GP gives him some addresses for websites where he can find stories from people who have had coronary angioplasty. He also gives Richard some leaflets with advice about giving up smoking and reducing cholesterol through diet. The GP suggests that Richard come back to see him in a couple of weeks, once he has had time to go through the information and think more about what he would like to do.

Resources

Coronary Angioplasty and Coronary Stent Implantation
All About Coronary Angiography

These brochures from the National Heart Foundation are plain English guides.

Phone: 1300 36 27 87

Website: <http://www.heartfoundation.com.au>

Coronary Angioplasty

This web page from the Fremantle Hospital and Health Service's Cardiology Testing Unit describes the procedure.

<http://www.fremantleheart.asn.au/309.html>

Angioplasty.org,

This United States website for healthcare consumers and professionals includes a guide to preparing for an appointment with a health professional:

<http://www.angioplasty.org/nv/youandyourmd.html>

The site also includes a general page on angioplasty:

<http://www.angioplasty.org/nv/angio101.html>

Preparing for coronary angioplasty: the patients' experiences

This article (Higgins et al 2001) examines how Australian healthcare consumers prepared for coronary angioplasty.

http://eprints.qut.edu.au/archive/00000435/01/Theobald_preparing.pdf

References

BeLue R, Butler J and Kuder J (2004). Implications of patient and physician decision making: an illustration in treatment options for coronary artery disease. *Journal of Ambulatory Care Management* 27(4):305–313.

Gulanick M, Bliley A, Perino B and Keough V (1997). Patients' responses to the angioplasty experience: a qualitative study. *American Journal of Critical Care* 6:25–32.

Higgins M, Dunn S and Theobald K (2001). Preparing for coronary angioplasty: the patients' experiences. *Australian Critical Care* 14(2):64–70. http://eprints.qut.edu.au/archive/00000435/01/Theobald_preparing.pdf

Kee F, McDonald P, Gaffney B (1997). Risks and benefits of coronary angioplasty: the patient's perspective: a preliminary study. *Quality Health Care* 6:131–139.

Tooth L, McKenna K, Maas F and McEniery P (1997). The effects of pre-coronary angioplasty education and counselling on patients and their spouses: a preliminary report. *Patient Education and Counseling* 32:185–196.

Case study 3: Medication intervention — glucocorticoids

Introduction

This case study looks in detail at a particular medication intervention — glucocorticoids. This section describes:

- what this medication is, the kind of situation in which it might be offered, and some of the factors that might influence the decision on whether to take the medication
- the current situation in communication of the medication
- published studies that illustrate how some of the principles of good communication, outlined in Part 1 of this toolkit, apply to glucocorticoids (note: for some of the principles, no relevant studies were found)

- a hypothetical example that illustrates how the principles apply in this situation
- relevant references.

Although this case study focuses on glucocorticoids, it highlights many issues that apply to other medications.

WHAT ARE GLUCOCORTICOIDS?

Glucocorticoids are a type of hormone or chemical messenger produced naturally by the body. They stimulate the breakdown of carbohydrates, fats and proteins to provide energy, particularly when the body is under stress. They also reduce inflammation and swelling, and suppress allergic reactions.

Glucocorticoids have been used for more than 50 years to treat a wide range of health conditions, such as asthma and allergies, some types of arthritis, skin conditions, cancers and hormonal problems. They can be given as tablets, creams or injections, or in liquid forms for inhalation through the nose or mouth, and for enemas. The length of time for which the medication is given and the dose will vary, depending on the form of glucocorticoid and the health condition being treated.

BALANCING THE BENEFITS AND RISKS

Glucocorticoids are an effective form of treatment for many conditions; however, they have a variety of potential side effects. When given in a low dose for a few days or even a few weeks, glucocorticoids do not usually cause long-term side effects, although some people experience short-term effects like difficulty sleeping. If glucocorticoids are given for longer periods, particularly in high doses, other side effects can occur. Some common side effects from long-term use are indigestion; weight gain and altered appearance; thinning of the skin (a particular problem in older people who already have skin problems caused by ageing); thinning of the bones; and increased susceptibility to infection. Less common side effects from long-term use include diabetes, facial hair, acne, cataracts and high blood pressure.

Taking glucocorticoids for a few weeks or more suppresses the body's own supply of the hormone, cortisone. Therefore, it is important not to stop taking these medications suddenly. Healthcare consumers planning to come off glucocorticoids should talk to their professionals about gradually reducing the dose, to allow the supplies of natural hormone to build up.

Most people can safely take glucocorticoids, provided they are carefully assessed and monitored and the lowest effective dose is used for the shortest feasible time. For many health conditions, symptoms are reduced after a few days of glucocorticoid treatment, which means that the dose can be tapered to a lower amount, to avoid the side effects of long-term treatment.

Where glucocorticoids are recommended, it is important for consumers and professionals to discuss the possible risks and benefits of the treatment in question. The consumer's age, overall health and personal preferences need to be taken into account, as does their health history, because glucocorticoids can aggravate certain conditions (for example, osteoporosis, tuberculosis, infections, diabetes and high blood pressure).

Current situation in communication about glucocorticoid treatments

The many negative connotations of glucocorticoids mean that some consumers given these medications may not stick to their treatment schedule because of concerns about the risks and lack of confidence in the benefits, as illustrated by the following study.

Study

Poor communication is linked to failure to stick to treatment

A study in the United States looked at 50 adults with moderate to severe asthma, and monitored their adherence to a treatment schedule (inhaled steroids, twice a day) over 42 days. The two factors most strongly linked with failure to stick to the medication regimen were less than 12 years of formal education and poor communication between the professional and the consumer. The results emphasised the importance of adequate communication between consumers and professionals.

Source: Apter et al 1998.

The section on the opposite page looks at studies that illustrate how the principles described in Part 1 of this toolkit apply to glucocorticoid treatment.

Applying the principles of good communication to decisions about treatment with glucocorticoids

A worthwhile outcome for a decision about glucocorticoids could be expressed as *healthcare consumers making an informed choice about whether or not to accept the medication, and feeling satisfied with both the decision that they have taken and their level of involvement in the process*. An informed decision in this case would be one that incorporates information about:

- the condition being treated
- the risks and benefits of the medication
- the risks and benefits of alternatives (such as doing nothing or taking alternative medications)
- the person's preferences
- the healthcare professional's advice (to the extent that this is desired by the person).

Despite the widespread use of glucocorticoids, the literature review on which this toolkit is based found few publications that looked at communication about these medications and their risks and benefits. The studies found are shown below.

PRINCIPLE 1: GOOD COMMUNICATION BETWEEN HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS HAS MANY BENEFITS

As shown by the study below, good communication can improve healthcare consumers' adherence to a treatment schedule.

Study

Good communication can improve adherence to treatment schedule

A study in the United States looked at whether improving communication could help healthcare consumers with asthma to use inhaled steroids more effectively. A group of consumers were assigned to either a treatment group (10 people) or a control group (9 people), and all received standard asthma care. Over 10 weeks, the researchers checked participants' medication use through an electronic device that recorded how much medication they were taking. Those in the treatment group received direct feedback from the professional, in the form of a constructive, positive and nonjudgmental discussion that emphasised techniques and strategies to improve adherence to the treatment regime, where necessary.

continued »

continued »

By the second week of the study, adherence to the treatment schedule increased to 81% in the treatment group, compared to 47% in the control group. Adherence remained above 70% in the treatment group for the entire trial, but decreased in the control group.

Source: Onyirimba et al 2003.

PRINCIPLE 4: PERCEPTIONS OF RISKS AND BENEFITS ARE COMPLEX, AND HEALTHCARE CONSUMERS AND HEALTHCARE PROFESSIONALS MAY HAVE DIFFERENT PRIORITIES

As shown by the study below, perceptions of risks and benefits in relation to glucocorticoid treatment are complex, and professionals may not realise that consumers obtain information about this type of medication from a range of sources.

Study

Healthcare professionals need to be aware that consumers obtain information from a range of sources

In a study in the United Kingdom, about 250 GPs responded to a series of scenarios about a hypothetical healthcare consumer (a 58-year-old woman) prescribed oral steroids. The story was based on analysis of 17 interviews with people recently prescribed oral steroids, which showed that four main sources influence consumers. These were:

- their own beliefs
- opinions of family and friends
- television
- a consumer information campaign.

These four influences were included in the description of the woman's consultations with a professional. For example, in one scenario, the woman does not take the tablets as prescribed because she thinks the dose is 'a bit high', and this belief has been reinforced by conversations with her daughter and neighbour.

The GPs surveyed were asked to judge whether the scenarios were realistic and to express how they felt about the way the consumer had behaved.

Where the scenarios presented the woman as being influenced by her own beliefs, the influence of family and friends and the television, only about half of the GPs felt that the scenarios were realistic. However, where the scenarios involved the consumer campaign as a source of information, more than 90% of the GPs found them realistic. Also, the GPs reported feeling more supportive and sympathetic towards the consumer campaign as a source of consumer information than towards advice given by family and friends.

The researchers suggest that developing 'common ground' will be difficult if GPs are not aware of, and sympathetic towards, the ways in which consumers use information from a range of sources to form beliefs that then affect their behaviour in taking medication.

Source: Stevenson et al 1999.

Example

The following example applies the principles to a hypothetical situation in which someone has been diagnosed with a condition that requires treatment by glucocorticoids. Since there are few publications about communication of this type of medication, the example is based partly on evidence and partly on the application of knowledge gained from communication of other medical conditions.

The example describes a series of consultations between Dr Singh, a general practitioner, and Mrs Green, a 65-year-old healthcare consumer, and is given from Dr Singh's point of view. The example covers a single consultation, although in reality this interaction would more likely take place over a series of consultations.

EXPLAINING THE CONDITION AND TREATMENT

Mrs Green is 65 years old and has been my patient for several years. She is quite fit and active, and helps her daughter by looking after her young grandson three mornings a week. She came in recently because she had suddenly found that her neck, shoulders and hips were sore and stiff, particularly in the morning. After examining her and asking a few more questions about her symptoms, I decided that she probably had polymyalgia rheumatica (PMR), so I organised blood tests. Mrs Green then came back to see me, to get the results of the tests.

When Mrs Green came in, we had a brief chat about her grandson, whom she had brought in a couple of months ago about a chest infection. We then talked about her symptoms, which were continuing to bother her. I explained the results of the tests, which suggested that she did have PMR. I talked to her about the likely course of the disease, including the fact that it normally persists for a year or two before resolving. I also downloaded a copy of a leaflet about the condition and printed it off for her to take away with her.²⁵ Mrs Green asked several questions and, based on what

25 http://www.arthritistasmania.com.au/arthritisinfo/facts/pdfs/polymyalgia_rheumatica.pdf

she was asking, I felt that she had a good understanding of my explanation of her condition. Also, she mentioned that she would use her daughter's computer to find out more about it from the internet. I encouraged her to do this, and suggested a couple of websites she might find useful. I also suggested that she write down any questions that came up through her researches, so that she could raise them with me next time she came in.

At this point, I talked about the risks if the condition were left untreated, explaining that in most cases there is no alternative highly effective treatment. I explained to Mrs Green that, if untreated, the symptoms would continue and she faced a small but significant chance of developing temporal arteritis. This condition can have potentially serious risks if untreated, including a 50% chance of irreversible blindness in one or other eye. Explaining the risks of not treating the condition often helps the consumer to put the possible side effects of glucocorticoids into perspective.

We then talked about treatment. I explained that the most effective course of action is a low dose of the steroid cortisone, given as tablets, for about a year or so, depending upon when the disease resolves. Mrs Green looked quite alarmed at this, which is a fairly normal reaction to the idea of being on the medication for so long (and also to the idea of taking steroids). I usually find that it's best to keep going and explain a bit more, before stopping to ask for questions. So I carried on to say that cortisone is really effective; that most people find that it gets rid of their symptoms completely within a very short period of time (often within a few days) and that some of my patients have told me it works so well it is like a miracle cure.

FINDING OUT ABOUT AND DEALING WITH CONCERNS

Mrs Green now looked a bit less alarmed. I asked if there was anything in what I'd been saying that she was worried about, and she said that she was worried about taking steroids, because she had a friend who took them for some years and eventually developed severe osteoporosis. I agreed that this could be a problem, particularly if she was taking the medication for about a year. I then went on to explain that we would check her bone density with a scan and would use various strategies to reduce this risk. We discussed some things that she could do to reduce her own risk of osteoporosis, such as ensuring that she has an adequate intake of calcium, that her vitamin D levels are satisfactory and that she gets sufficient exercise.

Although we had now dealt with the osteoporosis risk, I could see that Mrs Green was still bothered about something. In talking more, it eventually emerged that she was also worried about the idea of taking steroids because a well-known sportsman had recently been banned from running after a drug test found that he was positive for steroids.

To help put her concerns into perspective, I explained that steroids are something we all produce naturally and that cortisol is a hormone produced by our adrenal glands. We discussed how cortisone and other glucocorticoids in therapeutic doses (which are higher than what the body produces) are frequently used to treat diseases like polymyalgia, rheumatoid arthritis and many other conditions. I acknowledged that she may well have heard bad things about cortisone tablets from family or friends over the years, and that it does have a bad reputation. I then explained that cortisone is actually a highly effective drug in certain situations like polymyalgia, and that I would closely follow her progress to minimise any potential side effects. I also explained that the sportsman had probably been taking a very different type of steroid hormone than a glucocorticoid.

GIVING CLEAR INFORMATION

I told Mrs Green about the cortisone tablets that I would like her to take, and then ran through the possible side effects with her, first explaining that she didn't need to worry about trying to remember everything I was saying, because I would send her a letter telling her the same information I was giving her in the consultation. To explain the side effects, I said, 'One of the first things that some people notice is that they feel hungry — cortisone can increase the appetite, although often at higher doses than you will be taking. So, if you do feel hungry, try to direct your appetite to healthy foods rather than unhealthy ones. Over a period of time, cortisone can also cause weight gain and might also redistribute your body fat so you develop fullness in the cheeks and around the stomach. This is usually reversible when you stop the medicine but can take some time to fully disappear.'

I then discussed two possible, more serious side effects — the osteoporosis, which we had already covered, and the rare condition of *avascular necrosis* of bone. I explained that we don't exactly know how cortisone causes this problem, but that it results in a loss of blood supply to one or more joints (usually the hips) and often means that the joint has to be replaced at some time in the future. I made it clear that this side effect is rare and that we do

not have precise figures about the risk, but to put it in perspective I explained that it perhaps might affect 1 in 10,000 people taking steroids. I also emphasised that it is more likely to occur in people taking high doses of steroids for a long period of time, such as people with severe asthma.

CHECKING FOR UNDERSTANDING

Towards the end of the consultation, I brought up some of the things that Mrs Green needed to look out for and act on straight away if they occurred. I explained that cortisone treatment can bring out the symptoms of diabetes in people who are predisposed to the condition, and asked her to contact me straightaway if she noticed that she was thirstier than usual or going to the toilet a lot. I also said: 'If you see any other doctors for other problems, you must let them know that you are taking cortisone. This is important if you are having an operation, another medicine or even a vaccination, you must tell the doctor that you are taking cortisone. Also, it is important that you don't stop the tablets suddenly once you have been on them a while. We all produce cortisone and when you are on tablets, the body stops making as much because it can detect the extra cortisone in the system. Stopping suddenly might mean that you don't have enough cortisone in the system, and can lead to serious problems like a very low blood pressure.'

Because of the importance of these messages, I asked her to sum up those instructions. She remembered the main points and had obviously understood the information well. However, she had some questions about the risk of diabetes, because her sister has this condition. I again emphasised that the risks were small, because of the low dose, and reiterated the need for her to be on the lookout for any symptoms that might suggest onset of diabetes, and the fact that I would closely monitor her with blood tests if necessary, so that we could detect the problem quickly if it should occur.

SUMMING UP

Finally, I mentioned that I would monitor her blood pressure, as this could increase with the steroids, and that she might notice thinning of her skin and very easy bruising, but reassured her that these possible effects would cease once she stopped taking the drug. I then summed up all I had told her, and asked if she had any more questions. She was still worried about the diabetes, and I again went over the signs to look out for. I explained again that

I would send her a letter outlining all these potential side effects, and asked her to call me once she had read it if she had any further questions or was worried about something in particular.

I asked her to make another appointment for a few weeks time, and gave her a form to get another blood test just before that appointment, so that we could see whether the blood results improved as a result of the medication and to check her blood sugar.

Before she left, I said, 'If you are not feeling a great deal better in a few days I would like you to come back and see me straight away. Similarly, if you develop any new problems that you think might be related to taking this medicine, please make an appointment to see me.'

Resources

The website of *Arthritis Tasmania* includes a leaflet on polymyalgia rheumatica: http://www.arthritistasmania.com.au/arthritinfo/facts/pdfs/polymyalgia_rheumatica.pdf

References

Apter AJ, Reisine ST, Affleck G, Barrows E and ZuWallack RL (1998). Adherence with twice-daily dosing of inhaled steroids: socioeconomic and health-belief differences. *American Journal of Respiratory and Critical Care Medicine*. 157:1810–1817.

Onyirimba F, Apter A, Reisine S, Litt M, McCusker C, Connors M and ZuWallack R (2003). Direct clinician-to-patient feedback discussion of inhaled steroid use: its effect on adherence. *Annals of Allergy, Asthma and Immunology* 90:411–415.

Stevenson FA, Gerrett D, Rivers P and Wallace G (2000). GPs' recognition of, and response to, influences on patients' medicine taking: the implications for communication. *Family Practice* 17:119–123.

Relevant organisations, websites and resources

AUSTRALIAN ORGANISATIONS, WEBSITES AND RESOURCES

This list does not include information about organisations focusing on specific medical conditions. The Collective of Self-Help Groups and the Consumers Health Forum of Australia (details listed below) can provide information on such organisations.

All You Need to Know About a Healthy Pregnancy for a Healthy Baby — An Aboriginal Personal Pregnancy Handbook

A booklet produced by Illawarra Health, to promote healthy pregnancy and breastfeeding among Aboriginal women.

Address: Available from Division of Population Health and Planning, South Eastern Sydney and from Illawara Health, Division of Population Health and Planning, Suite 3d, 145–149 King St, Warrawong, NSW 2502

Phone: 02 4255 2200

Australian Competition and Consumer Commission

The Australian Competition and Consumer Commission (ACCC) has developed an information kit for healthcare professionals title *Straight Talking with your Patients*, which includes suggestions on providing information and disclosure of fees to healthcare consumers.

Website: <http://www.accc.gov.au>

Australian Competition and Consumer Commission

The Australian Competition and Consumer Commission (ACCC) has developed an information kit for healthcare professionals title *Straight Talking with your Patients*, which includes suggestions on providing information and disclosure of fees to healthcare consumers.

Website: <http://www.accc.gov.au>

Australian Commission on Safety and Quality in Health Care

This site includes links to *10 Tips for Safer Health Care* and the *National Patient Safety Education Framework Bibliography*.

Address: MDP 46, GPO Box 9848, Canberra, ACT 2601

Phone: 02 6289 4244

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

Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer

The National Breast Cancer Centre and the National Cancer Control Initiative have developed guidelines for the psychosocial care of adults with cancer. These guidelines expand on those developed for women

with breast cancer, to provide recommendations for clinical care of all adult healthcare consumers with cancer.

Phone: (National Breast Cancer Centre) 1800 624 973

Website: <http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm>

Cochrane Collaboration and Cochrane Consumer Network

The Cochrane Collaboration is an international not-for-profit organisation, providing up-to-date information about the effects of healthcare.

Website: <http://www.cochrane.org/index0.htm>

The Cochrane Consumer Network aims to provide consumer input into developing Cochrane systematic reviews of best evidence in healthcare and in using this evidence.

Website: <http://www.cochrane.org/consumers/homepage.htm>

Collective of Self-Help Groups

COSHG aims to develop the self-help movement, promote individual's rights, develop and encourage links between groups, and to be a resource and backup for self-help groups.

Address: PO Box 251, Brunswick East, Vic 3057

Phone: 03 9349 2301

Website: <http://home.vicnet.net.au/~coshg/welcome.html>

Consumers' Health Forum of Australia

The forum is a national organisation providing a voice for all consumers. Its members include consumer organisations that represent a broad range of consumers such as illness groups, disability groups and specific population groups (youth, older people, women, etc).

Address: PO Box 3099, Manuka, ACT 2603

Phone: (02) 6273 5444

Website: <http://www.chf.org.au>

Health *Insite*

An initiative of the Australian Government, this website provides a wide range of up-to-date and quality assessed information on important health topics such as diabetes, cancer, mental health and asthma.

Website: <http://www.healthinsite.gov.au>

The website has a page about assessing health information from the web, and many links to other assessment tools.

Assessment: http://www.healthinsite.gov.au/topics/How_to_Assess_Health_Information_Online

Health Consumers' Council (Western Australia)

The council is an independent community-based organisation, representing the healthcare consumer's 'voice' in health policy, planning, research and service delivery. The council's site includes a questionnaire entitled *Questions to Ask Your Doctor*:

Address: GPO Box C134, Perth, WA 6839

Phone: 08 9221 3422; Freecall: 1800 620 780

Website: <http://www.hcc-wa.global.net.au>

Questionnaire: http://www.hcc-wa.global.net.au/pages/questions_doc.html

Health Matters consumer guides

These guides, produced by the Australian Broadcasting Corporation (ABC), are designed to help healthcare consumers make sense of medical research and get the most out of their professional care.

Address: 4th Floor, ABC Ultimo Centre, GPO Box 9994, Sydney, NSW 2001

Phone: 139994

Website: <http://www.abc.net.au/health/cguides/default.htm>

(including *Cancer screening: Is it worth it?*

<http://www.abc.net.au/health/thepulse/s1438910.htm>

and *Cancer screening — Benefits and Harms* <http://www.abc.net.au/rn/talks/8.30/helthprt/stories/s1440410.htm>)

Human Behaviour and Health Research Unit (Flinders University, South Australia)

The unit is a centre for research, evaluation and development of chronic condition management. This includes coordinated care, care planning, behavioural change and self management, and the education and training of healthcare professionals and healthcare consumers.

Address: GPO PO Box 2100, Adelaide, SA 5001

Phone: 08 8404 2323

Website: <http://som.flinders.edu.au/FUSA/CCTU/home.html>

Informedhealthonline

This site is produced by the Health Research and Education Foundation Ltd, a health promotion charity based in Melbourne. The foundation aims to provide information and resource tools that enable people to keep up to date with reliable, evidence-based information. It promotes research literacy, and individual and community use of high-quality research.

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

Koori Women's 'Baby Blues'

Illawara Health has published a pamphlet (*Koori Women's 'Baby Blues' — Postnatal Depression in the Aboriginal Community*) and a booklet (*Koori Women's 'Baby Blues' — A Project about Aboriginal Women and their Feelings after having a Baby*) to raise awareness of postnatal depression in Aboriginal communities in the Illawara and Shoalhaven.

Address: Available from Division of Population Health and Planning, South Eastern Sydney and from Illawara Health, Division of Population Health and Planning, Suite 3d, 145–149 King St, Warrawong, NSW 2502

Phone: 02 4255 2200

Medimate

This consumer brochure is produced by the National Prescribing Service. Its aim is to help healthcare consumers to find, understand and use information about medicines. It encourages consumers to do this in partnership with their healthcare professionals. Medimate covers prescription medicines, over-the-counter medicines and natural and herbal medicines. It is available in several other languages — Chinese, Greek, Italian and Vietnamese.

Address: PO Box 1147, Strawberry Hills NSW 2012

Phone: 02 8217 8700

Website: http://www.nps.org.au/resources/content/medimate_brochure.pdf

Multicultural Equity and Access Program (MEAP)

This program, which is funded by the Victorian Department of Human Services, aims to develop and implement strategies to improve access to home and community care funded services in the Eastern Region of Melbourne, for people from culturally and linguistically diverse backgrounds.

Address: 333 Mitcham Road, Mitcham, VIC 3132

Phone: 03 9873 1666

Website: <http://www.miceastmelb.com.au/meap.htm>

MEAP's Migrant Information Centre has produced the *Home and Personal Care Kit*. The guides service providers in culturally sensitive care and effective communication with people of culturally and linguistically diverse backgrounds.

Website: <http://www.miceastmelb.com.au/meap.htm>

Multicultural Health Communication Service

The New South Wales Multicultural Health Communication Service assists healthcare professionals to communicate with non-English speaking communities throughout the state. The site includes more than 12,000 health resources in 35 languages (with new publications added regularly), links to related websites and to multilingual resources produced by other services. The organisation also has a Health Care Interpreter Service

Phone: 02 9382 7516

Website: <http://www.mhcs.health.nsw.gov.au/>

Interpreter service:

Phone: 02 9515 3222

Website: <http://www.mhcs.health.nsw.gov.au/health-public-affairs/mhcs/publications/4300.html>

National Cancer Control Initiative

The National Cancer Control Initiative (NCCI) is an expert reference body that provides advice, identifies appropriate initiatives and makes recommendations to the Australian Government and other groups about the prevention, detection, treatment and palliation of cancer for all Australians.

Address: 1 Rathdowne Street, Carlton Vic. 3053

Phone: 03 9635 5108

Website: <http://www.ncci.org.au/>

National Institute of Clinical Studies

The National Institute of Clinical Studies (NICS) aims to improve health care by helping to bridge the gap between what we know (the research findings) and what we do (day-to-day clinical practice).

Address: Fawkner Centre Level 5, 499 St Kilda Road, Melbourne, Vic. 3004

Phone: 03 8866 0400

Website: <http://www.nicsl.com.au>

As part of a national program to improve diagnosis and treatment of heart failure, and improve the standard of information available to healthcare consumers, NICS has produced the NICS Heart Failure Resources Directory, which brings together four high-quality evidence-based resources identified by the study.

Website: <http://www.nicsl.com.au/projects.aspx>

In collaboration with the Australasian Cochrane Centre, NICS has developed a guide to help healthcare consumers and healthcare professionals to navigate the Cochrane Library. The online guide describes the history and structure of the library, and provides detailed tutorials on how to use the library databases.

Website: <http://www.nicsl.com.au/cochrane/guide.asp>

Sharing the True Stories

This website is aimed at improving communication between health staff and Aboriginal and Torres Strait Islander clients. Still in development, the site currently focuses on communication between health staff and one group of Aboriginal people (the Yolnu from northeast Arnhemland), but will expand to other areas of service delivery and other language groups.

Phone: 08 8941 1162

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

National Health and Medical Research Council

The National Health and Medical Research Council (NHMRC) advises the Australian community and the Australian Government, and state and territory governments, on standards of individual and public health, and supports research to improve those standards. The activities of the NHMRC translate into four main outputs: health and medical research; health policy and advice; health ethics; and the regulation of research involving donated IVF embryos, including monitoring compliance with the ban on human cloning and certain other activities. A regular publishing program ensures that the council's recommendations are widely available to governments, the community, scientific, industrial and educational groups.

Website: <http://www.nhmrc.gov.au>

NHMRC publications include a series of booklets that offer information and advice to health professionals and to consumers about the use of HRT.

<http://www.nhmrc.gov.au/publications/synopses/wh35syn.htm>

National Prescribing Service

This member-based organisation, funded by the Australian Government Department of Health and Ageing, provides accurate, balanced, evidence-based information and services to healthcare professionals and the community on quality use of medicines (QUM). It works with GPs, pharmacists, specialists, other healthcare professionals, government, the pharmaceutical industry, consumer organisations and the community.

Website: <http://www.nps.org.au>

Screening and Test Evaluation Program (STEP)

The STEP program at the University of Sydney is looking at the use of decision aids for screening, at the accuracy and outcomes of screening and diagnostic tests, and at informed decision-making in such tests.

Website: <http://www.health.usyd.edu.au/step/>

Smart Health Choices: How to Make Informed Health Decisions

Book by J Irwig, L Irwig and M Sweet (1999), Allen & Unwin, NSW, Australia.

State and territory health departments

Australian Capital Territory: ACT Health

Address: GPO Box 825, Canberra, ACT 2601

Phone: 13 22 81

Website: <http://www.health.act.gov.au/c/health>

New South Wales: NSW Health

Address: Locked Mail Bag 961, North Sydney, NSW 2059

Phone: 02 9391 9000

Website: <http://www.health.nsw.gov.au>
(includes *Living* website for consumers — <http://www.health.nsw.gov.au/living/index.html>)

Northern Territory: Department of Health and Community Services

Address: PO Box 40596, Casuarina, NT 0811

Phone: 08 8999 2400

Website: <http://www.nt.gov.au/health/index.shtml>

Queensland: Queensland Health

Address: GPO Box 48, Brisbane, Qld 4001

Phone: 07 3234 0111

Website: <http://www.health.qld.gov.au>

South Australia: South Australia Department of Health

Address: PO Box 287, Rundle Mall, Adelaide SA 5001

Phone: 08 8226-6000

Website: <http://www.health.sa.gov.au>
(includes *HealthySA* website for consumers — <http://www.healthysa.sa.gov.au>)

Tasmania: Department of Health and Human Services

Address: 34 Davey Street, Hobart, Tas. 7000

Phone: 03 6233 3185

Website: <http://www.dhhs.tas.gov.au>
(includes *Healthy Living* website for consumers — <http://www.dhhs.tas.gov.au/healthyliving>)

Victoria: Department of Human Services

Address: GPO Box 4057, Melbourne, Vic. 3001

Phone: 03 9616 7777

Website: <http://hnp.dhs.vic.gov.au>
(includes *Better Health* website for consumers — <http://www.betterhealth.vic.gov.au>)

Western Australia: Health Department of Western Australia
Address: PO Box 8172, Perth Business Centre, Perth, WA 6849
Phone: 08 9222 4222
Website: <http://www.health.wa.gov.au>
(includes *HealthWay* website for consumers — <http://www1.healthway.wa.gov.au>)

Translating and interpreting services

The Health Insurance Commission has a translating/interpreting service on its *Your Health* website. The New South Wales Multicultural Health Communication Service (see above) also has a Health Care Interpreter Service.

Phone: 131 450
Website: <http://www.hic.gov.au/yourhealth/>

INTERNATIONAL ORGANISATIONS, WEBSITES AND RESOURCES

Bandolier (United Kingdom)

Bandolier is a monthly independent journal about evidence-based healthcare, written by Oxford scientists. The journal is an important source of evidence-based healthcare information worldwide, for both healthcare consumers and healthcare professionals.

Address: Bandolier Office, Pain Research, The Churchill, Oxford OX3 7LJ,
UK
Phone: (44) 1865 226132
Website: <http://www.jr2.ox.ac.uk/bandolier/index.html>

Center for Health Care Strategies (United States)

The centre aims to induce states, health plans and consumer groups, through technical assistance and training, to engage in activities to improve quality of healthcare. Factsheets produced by the centre include one entitled *Resources for Health Literacy Information and Publications*, which provides a list of materials developed for particular conditions and groups of consumers.

Address: P.O. Box 3469, Princeton,
NJ 08543-3469, United States
Phone: (609) 895 8101
Website: <http://www.chcs.org>

DIPEX — Database of Individual Patient Experiences (United Kingdom)

DIPEX is a site containing narratives of consumers' experiences. It shows healthcare consumers where to find a wide variety of personal experiences of health and illness. Consumers can watch, listen to or read the interviews, and find reliable information on treatment choices and where to find support.

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

DISCERN (United Kingdom)

DISCERN is an online guide to help healthcare consumers assess health information available in print or on the web.

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

Friendly coaching for tough decisions

Website developed by the Ottawa Health Research Institute in Canada. The site includes a list of the many decision aids developed worldwide that meet the criteria for inclusion on the site.

List of aids: <http://decisionaid.ohri.ca/index.html>

The same site also has an online decision support tool:

Decision support tool: <http://decisionaid.ohri.ca/decguide.html>

Health Crossroads (United States)

This site provides decision support to individuals making choices about their healthcare, based on the concept of shared decision making. Its aim is to help healthcare consumers to become informed about their medical options, communicate effectively with healthcare professionals, and achieve better overall health outcomes.

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

Health on the Net Foundation (Switzerland)

The Health on the Net Foundation (HON), created in 1995, is a non-governmental organisation based in Switzerland. Its mission is to guide healthcare consumers and healthcare professionals to useful and reliable online medical and health information. The organisation also works on setting ethical standards for website developers.

Website: <http://www.hon.ch/>

Information on self-efficacy

A list of resources about self-efficacy, produced by the Emory University in the United States. Includes information on what self-efficacy is, how it differs from confidence, etc.

Website: <http://www.emory.edu/EDUCATION/mfp/self-efficacy.html>

International Patient Decision Aid Standards (IPDAS) Collaboration
Brings together people from around the world who design, test, compile, provide, or use consumer decision aids. The aim of the collaboration is to reach agreement about how to judge the quality of a decision aid. IPDAS has recently published a discussion document on setting standards for decision aids.

Website: <http://ipdas.ohri.ca/index.html>

National Health Service Cancer Screening Programme (United Kingdom)

This programme provides a range of information for healthcare consumers on screening for breast, cervical, prostate and bowel cancer. Materials available from the website include:

- a leaflet entitled *Breast Screening: The Facts* — available in 18 languages
- a leaflet entitled *Cervical Screening: The Facts* — available in 20 languages
- picture leaflets for women with learning disabilities, to tell them about breast and cervical screening, and where they can find more information
- an information sheet for men considering a PSA test
- information on bowel cancer (the signs and symptoms, how many people get the disease, how many people die of it and what the risk factors are).

Address: Fulwood House, Old Fulwood Road, Sheffield S10 3TH, United Kingdom

Phone: (0114) 271 1060

Website: <http://www.cancerscreening.nhs.uk>

National Electronic Library for Health (United Kingdom)

The library aims to provide clinicians with access to the best current know-how and knowledge to support healthcare-related decisions.

Website: <http://www.nelh.nhs.uk>

NHS Direct Online (United Kingdom)

This site provides a gateway to health information for consumers.

Website: <http://www.nhsdirect.nhs.uk/>

The Resourceful Patient (United Kingdom)

Web-based book and toolkit.

Address: Rosetta, 59 Lakeside, Oxford OX2 8JQ, United Kingdom

Website: <http://www.resourcefulpatient.org/index.htm>.

BIBLIOGRAPHY

An asterisk * after a reference indicates that the study was a systematic review.

Abbott SA (1998). The benefits of patient education. *Gastroenterology Nursing* 21:207–209.

ACSQHC (Australian Council for Safety and Quality in Health Care) (2003) *10 Tips for Safer Health Care*.

AHMAC (Australian Health Ministers' Advisory Council (2004). *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009*, Department of Health, South Australia.

AMA (American Medical Association) (1999). Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. *Journal of the American Medical Association* 281:552–557.

Anderson D (1977). Shared decision-making programs: descriptive analysis of experience with shared decision-making programs in VA. A systematic review: assessing the effectiveness of shared decision-making programs for prostate care. *Technology Assessment Program Report No. 6*. Management Decision and Research Centre, Health Services Research and Development Services, Veterans Health Administration, United States.*

Apter AJ, Reisine ST, Affleck G, Barrows E and ZuWallack RL (1998). Adherence with twice-daily dosing of inhaled steroids: Socioeconomic and health-belief differences. *American Journal of Respiratory and Critical Care Medicine*. 157:1810–1817.

Arouni AJ and Rich EC (2003). Physician gender and patient care. *Journal of Gender-Specific Medicine* 6:24–30.

Australian Bureau of Statistics (ABS) (1996). *Aspects of Literacy: Assessed Skill Levels*. Canberra.

Baade PD, Steginga SK, Pinnock C and Aitken JF (2005). Communicating prostate cancer risk: What should we be telling our patients? *Medical Journal of Australia* 182:379–381. http://www.mja.com.au/public/issues/182_09_020505/baa10588_fm.html

Baade P, Steginga S et al (in press). Telling the story about prostate cancer risk: a challenge in risk communication. *Medical Journal of Australia*.

Barratt AL (2005). *Cancer screening: Is it worth it? Health Matters*, The Pulse, Australian Broadcasting Company.
<http://www.abc.net.au/health/thepulse/s1438910.htm>

Barratt AL, Irwig LM, Glasziou PP, Salkeld GP and Houssami N (2002). Benefits, harms and costs of screening mammography in women 70 years and over: a systematic review. *Medical Journal of Australia* 176:266–271.*
http://www.mja.com.au/public/issues/176_06_180302/bar10315.html

Barratt A, Trevena L, Davey HM and McCaffery K (2004). Use of decision aids to support informed choices about screening. *British Medical Journal* 329:507–510.

Barratt A, Howard K, Irwig L, Salkeld G and Houssami N (2005). Model of outcomes of screening mammography: information to support informed choices. *British Medical Journal* 330:936–940.
<http://bmj.bmjournals.com/cgi/content/full/330/7497/936>

Beck RS, Daughtridge R and Sloane PD (2002). Physician–patient communication in the primary care office: a systematic review. *Journal of the American Board of Family Practice* 15:25–38.*

Bedell SE, Graboys TB, Bedell E and Lown B (2004). Words that harm, words that heal. *Archives of Internal Medicine* 164:1365–1368.

Bekker H, Thornton JG, Airey CM, Connelly JB, Hewison J, Lilleyman J, MacIntosh M, Maule AJ, Michie S, Pearman AD and Robinson MB (1999). Informed decision making: an annotated bibliography and systematic review. *Health Technology Assessment* 3:1–156.*

BeLue R, Butler J and Kuder J (2004). Implications of patient and physician decision making: an illustration in treatment options for coronary artery disease. *Journal of Ambulatory Care Management* 27(4):305–313.

Bessell TL, McDonald S, Silagy CA, Anderson JN, Hiller JE and Sansom LN (2002). Do internet interventions for consumers cause more harm than good? A systematic review. *Health Expectations* 5:28–37.*

Bolden GB (2000). Towards understanding practices of medical interpreting: interpreters' involvement in history taking. *Discourse Studies* 2:387–419.

Bottorff JL, Ratner PA, Johnson JL, Lovato CY and Joab SA (1998). Communicating cancer risk information: the challenges of uncertainty. *Patient Education and Counseling* 33:67–81.

Broughton S (2002). A review of the literature: interventions to maximize capacity to consent and reduce anxiety of women with learning disabilities preparing for a cervical smear test. *Health Services Management Research* 15:173–85.*

Brown RF, Butow PN, Ellis P, Boyle F and Tattersall MH (2004). Seeking informed consent to cancer clinical trials: describing current practice. *Social Science and Medicine* 58:2445–2457.

Bryce S (2002). Lessons learnt from East Arnhem Land. Improving adherence to chronic disease treatments. *Australian Family Physician* 31:617–621.

Burkell J (2004). What are the chances? Evaluating risk and benefit information in consumer health materials. *Journal of the Medical Library Association* 92:200–208.

Chan EC, Haynes MC, O'Donnell FT, Bachino C and Vernon SW (2003a). Cultural sensitivity and informed decision making about prostate cancer screening. *Journal of Community Health* 28:393–405.

Chan EC, Vernon SW, O'Donnell FT, Ahn C, Greisinger A and Aga DW (2003b). Informed consent for cancer screening with prostate-specific antigen: how well are men getting the message? *American Journal of Public Health* 93:779–785.

Charles C, Whelan T and Gafni A (1999). What do we mean by partnership in making decisions about treatment? *British Medical Journal* 319:780–782.

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

Chew M (2005). What GPs want: time and time again. *Medical Journal of Australia* 183:58–59. http://www.mja.com.au/public/issues/183_02_180705/che10466_fm.html

Clancy CM, Cebul RD and Williams SV (1988). Guiding individual decisions: a randomized, controlled trial of decision analysis. *The American Journal of Medicine* 84: 283–288.

Clerehan R, Buchbinder R and Moodie J (2005). A linguistic framework for assessing the quality of written patient information: its use in assessing methotrexate information for rheumatoid arthritis. *Health Education Research* 20:334–344.

Clode D and Boldero J (2005). *Keeping the Doctor Alive: A Self-Care Guidebook for Medical Practitioners*, Royal Australian College of General Practitioners: South Melbourne.

Collins S, Drew P, Watt I and Entwistle V (in press). ‘Unilateral’ and ‘bilateral’ practitioner approaches in decision-making about treatment. *Social Science and Medicine*.

Coulter A (1997). Partnerships with patients: the pros and cons of shared clinical decision-making. *Journal of Health Services Research and Policy* 2:112–121.

Cowap S (2005). Time trials. *Medical Journal of Australia* 183:72. http://www.mja.com.au/public/issues/183_02_180705/cow10451_fm.html

Degner LF and Sloan JA (1992). Decision making during serious illness: what role do patients really want to play? *Journal of Clinical Epidemiology* 45:941–950.

Department of Health (UK) (2001). *The Expert Patient: A New Approach to Chronic Disease for the 21st Century*. London, Department of Health.

Deyo RA (2001). A key medical decision maker: the patient. *British Medical Journal* 323:466–467.

Dreger V and Tremback T (2002). Optimize patient health by treating literacy and language barriers. *Association of Operating Room Nurses Journal* 75:280–293.

Dudley T and Nagle J (2005). Enhancing your practice: How to explain risk to patients: Screening for prostate cancer. *Patient Care*. <http://www.patientcareonline.com/patcare/article/articleDetail.jsp?id=165978>

Dunn AS, Shridharani KV, Lou W, Bernstein J and Horowitz CR (2001). Physician–patient discussions of controversial cancer screening tests. *American Journal of Preventive Medicine* 20:130–134.

Edwards A (2003). Communicating risks. *British Medical Journal* 327:691–692.

Edwards A and Elwyn G (2001a). Risks — listen and don't mislead. *British Journal of General Practice* 51:259–260.

Edwards A and Elwyn G (2001b). Understanding risk and lessons for clinical risk communication about treatment preferences. *Quality in Health Care* 10(Suppl):i9–i13.

Edwards A, Elwyn G and Gwyn R (1999). General practice registrar responses to the use of different risk communication tools in simulated consultations: a focus group study. *British Medical Journal* 319:749–752.

Edwards A, Elwyn G, Covey J, Matthews E and Pill R (2001). Presenting risk information — a review of the effects of 'framing' and other manipulations on patient outcomes. *Journal of Health Communication* 6:61–82.*

Edwards A, Elwyn G and Mulley AI (2002). Explaining risks: turning numerical data into meaningful pictures. *British Medical Journal* 324:827–830.

Edwards A, Unigwe S, Elwyn G and Hood K (2005). Personalised risk communication for informed decision making about entering screening programs (Cochrane Review).* <http://www.update-software.com/Abstracts/ab001865.htm>

Eggly S (2002). Physician–patient co-construction of illness narratives in the medical interview. *Health Communication* 14:339–360.

Elwyn G and Gwyn R (1999). Narrative based medicine: stories we hear and stories we tell: analysing talk in clinical practice. *British Medical Journal* 318:186–188.

Elwyn G, Edwards A, Gwyn R and Grol R (1999). Towards a feasible model for shared decision making: focus group study with general practice registrars. *British Medical Journal* 319:753–756.

Entwistle V (2004). Trust and shared decision-making: an emerging research agenda. *Health Expectations* 7:271–273.

Entwistle V, Williams B, Skea Z, MacLennan G and Bhattacharya S (in press). Which surgical decisions should patients participate in and how? Reflections on women's recollections of discussions about variants of hysterectomy. *Social Science and Medicine*.

Epstein RM, Alper BS and Qill TE (2004). Communicating evidence for participatory decision making. *Journal of the American Medical Association* 291:2359–2365.

Farrell K, Ferguson E, James V and Lowe KC (2001). Confidence in the safety of blood for transfusion: the effect of message framing. *Transfusion* 41:1335–1340.

Farrell MH, Murphy MA and Schneider CE (2002). How underlying patient beliefs can affect physician–patient communication about prostate-specific antigen testing. *Effective Clinical Practice* 5:120–129.

Federman DG, Goyal S, Kamina A, Peduzzi P and Concato J (1999). Informed consent for PSA screening: does it happen? *Effective Clinical Practice* 2:152–157.

Frosch DL, Kaplan RM and Felitti V (2001). Evaluation of two methods to facilitate shared decision making for men considering the prostate-specific antigen test. *Journal of General Internal Medicine* 16:391–398.

Frosch DL, Kaplan RM and Felitti VJ (2003). A randomized controlled trial comparing Internet and video to facilitate patient education for men considering the prostate specific antigen test. *Journal of General Internal Medicine* 18:781–787.

Garretson S (2004). Benefits of pre-operative information programs. *Nursing Standard* 18:33–37.

Gattellari M and Ward JE (2003). Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomized controlled trial. *Journal of Medical Screening* 10:27–39.

Gattellari M and Ward JE (2005). Men's reactions to disclosed and undisclosed opportunistic PSA screening for prostate cancer. *Medical Journal of Australia* 182:386–389.
http://www.mja.com.au/public/issues/182_08_180405/gat10770_fm.html

Gazmararian JA, Williams MV, Peel J and Baker DW (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling* 51:267–275.

Gigerenzer G and Edwards A (2003). Simple tools for understanding risks: from innumeracy to insight. *British Medical Journal* 327:741–744.

Glasziou P, Del Mar C and Salisbury J (2003). *Evidence-Based Medicine Workbook: Finding and Applying the Best Research Evidence to Improve Patient Care*. BMJ Books, London.

- Grey MJA (2002). *The Resourceful Patient*. Rosetta Press, UK.
<http://www.resourcefulpatient.org/index.htm>
- Gulanick M, Bliley A, Perino B and Keough V (1997). Patients' responses to the angioplasty experience: a qualitative study. *American Journal of Critical Care* 6:25–32.
- Hall JA and Roter DL (1998). Medical communication and gender: a summary of research. *Journal of Gender-Specific Medicine* 1:39–42.
- Harrington J, Nobel LM and Newman SP (2004). Improving patients' communication with doctors: a systematic review of intervention studies. *Patient Education and Counseling* 52:7–16.*
- Hibbard JH and Peters E (2003). Supporting informed consumer healthcare decisions: data presentation approaches that facilitate the use of information in choice. *Annual Review of Public Health* 24:413–433.
- Higgins M, Dunn S and Theobald K (2001). Preparing for coronary angioplasty: the patients' experiences. *Australian Critical Care* 14(2):64–70.
http://eprints.qut.edu.au/archive/00000435/01/Theobald_preparing.pdf
- Hoffrage U, Lindsey S, Hertwig R and Gigerenzer G (2000). Communicating statistical information. *Science* 290:2261–2262.
- Huang X, Butow P, Meiser B and Goldstein D (1999). Attitudes and information needs of Chinese migrant cancer patients and their relatives. *Australian and New Zealand Journal of Medicine* 29:207–213.
- Irwig J, Irwig L and Sweet M (1999). *Smart Health Choices: How to Make Informed Health Decisions*, Allen & Unwin, NSW, Australia.
- Johnson A, Stanford J and Tyndall J (2005). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home (Cochrane review).* <http://www.update-software.com/Abstracts/ab003716.htm>
- Kakai H, Maskarinec G, Shumay DM, Tatsumura Y and Tasaki K (2003). Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. *Social Science and Medicine* 56:851–862.

- Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J and Rompa D (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine* 18:325–331.
- Kaplan RM, Hammel B and Schimmel LE (1985). Patient information processing and the decision to accept treatment. *Journal of Social Behavior and Personality* 1:113–120.
- Kassirer JP (1994). Incorporating patients' preferences into medical decisions. *New England Journal of Medicine* 330:1895–1896.
- Kee F, McDonald P and Gaffney B (1997). Risks and benefits of coronary angioplasty: the patient's perspective: a preliminary study. *Quality Health Care* 6:131–139.
- Kravitz RL (2001). Measuring patients' expectations and requests. *Annals of Internal Medicine* 134:881–888.
- Kravitz RL and Melnikow J (2001). Engaging patients in medical decision making. *British Medical Journal* 323:584–5.
- Kuhberger A (1998). The influence of framing on risky decisions: a meta-analysis. *Organizational Behaviour and Human Decision Processes* 75:23–55.
- Latham CE (1998). Is there data to support the concept that educated, empowered patients have better outcomes? *Journal of the American Society of Nephrology* 9:S141–144.
- Levine M and Whelan T (2001). Decision-making process — communicating risk/benefits: is there an ideal technique? *Journal of the National Cancer Institute Monographs* 30:143–145.
- Llewellyn-Thomas HA (1997). Investigating patients' preferences for different treatment options. *Canadian Journal of Nursing Research* 29:45–64.
- Lloyd AJ (2001). The extent of patients' understanding of the risk of treatments. *Quality in Health Care* 10:i14–i18.
- Lowe KC and Ferguson E (2003). Benefit and risk perceptions in transfusion medicine: blood and blood substitutes. *Journal of Internal Medicine* 253:498–507.
- Malone C (2003). Provision of information to patients in an NHS IVF unit. *Human Fertility* 6:26–29.
- Mazur DJ and Hickam DH (1993). Patients' and physicians' interpretations of graphic data displays. *Medical Decision Making* 13:59–63.

McCray AT (2005). Promoting health literacy. *Journal of the American Medical Information Association* 12:152–163.

McNutt RA (2004). Shared medical decision making. Problems, process, progress. *Journal of the American Medical Association* 292:2516–2518.

MEAP (Multicultural Equity and Access Program) (2004). *Home and Personal Care Kit: Cultural and Religious Profiles to Assist in Providing Culturally Sensitive Care and Effective Communication*. Home and Community Care and Migrant Information Centre, Melbourne.

Molenaar S, Sprangers MA, Rutgers EJ, Luiten EJ, Mulder J, Bossuyt PM, van Everdingen JJ, Oosterveld P and de Haes, HC (2001). Decision support for patients with early-stage breast cancer: effects of an interactive breast cancer CDROM on treatment decision, satisfaction, and quality of life. *Journal of Clinical Oncology* 19:1676–1687.*

Montgomery AA and Fahey T (2001). How do patients' treatment preferences compare with those of clinicians? *Quality in Health Care* 10:i39–i43.

Morgan MW, Deber RB, Llewellyn-Thomas HA, Gladstone P, Cusimano RJ, O'Rourke K, Tomlinson G and Detsky AS (2000). Randomized, controlled trial of an interactive videodisc decision aid for patients with ischemic heart disease. *Journal of General Internal Medicine* 15:685–693.

Moxey A, O'Connell D, Mcgettigan P and Henry D (2003). Describing treatment effects to patients. How they are expressed makes a difference. *Journal of General Internal Medicine* 18:948–959.

Mullet E, Ciudad N and Riviere-Shafighi S (2004). Cognitive processes involved in the assessment of health hazards' severity. *Health Risk and Society* 6: 277–288.

NHMRC (National Health and Medical Research Council) (2000). *How to Use the Evidence: Assessment and Application of Scientific Evidence*. Commonwealth of Australia, NHMRC, Canberra.

NHMRC (National Health and Medical Research Council) (2004a). *Communicating with Patients: Advice for Medical Practitioners*. Commonwealth of Australia, NHMRC, Canberra.

NHMRC (2004b). *General Guidelines for Medical Practitioners on Providing Information to Patients*. Commonwealth of Australia, NHMRC, Canberra.

NHMRC (National Health and Medical Research Council) (2006). *Cultural Competency in Health: a guide for policy, planning and practice*. Commonwealth of Australia NHMRC, Canberra.

NHS (National Health Service) Centre for Reviews and Dissemination (2000). *Effective Health Care: Informing, Communicating and Sharing Decisions with People who have Cancer*. Royal Society of Medicine Press.

O'Connor A (2001). Using patient decision aids to promote evidence-based decision making. *Evidence-Based Medicine* 6:100–102.

O'Connor AM, Fiset V, DeGrasse C, Graham ID, Evans W, Stacey D, Laupacis A, Tugwell P (1999). Decision aids for patients considering options affecting cancer outcomes: evidence of efficacy and policy implications. *Journal of the National Cancer Institute Monographs* 67–80.

O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, Holmes-Rovner M, Barry M, Jones J (1999). Decision aids for patients facing health treatment or screening decisions: systematic review. *British Medical Journal* 319:731–734.*

O'Connor AM, Legare F and Stacey D (2003). Risk communication in practice: the contribution of decision aids. *British Medical Journal* 327:736–740.

O'Connor A, Llewellyn-Thomas H and Stacey D (2005). Background document, International Patient Decision Aid Standards (IPDAS) Collaboration.

O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M and Jones J. Decision aids for people facing health treatment or screening decisions (Update in Cochrane Database of Systematic Reviews, 2003, CD001431, PMID:12804407).* <http://www.update-software.com/Abstracts/ab001431.htm>

O'Dell KJ, Volk RJ, Cass AR and Spann SJ (1999). Screening for prostate cancer with the prostate-specific antigen test: are patients making informed decisions? *Journal of Family Practice* 48:682–688.

O'Meara JJ, McNutt RA, Evans AT, Moore SW and Downs SM (1994). A decision analysis of streptokinase plus heparin as compared with heparin alone for deep-vein thrombosis. *New England Journal of Medicine* 330:1864–1869.

Onyirimba F, Apter A, Reisine S, Litt M, McCusker C, Connors M and ZuWallack R (2003). Direct clinician-to-patient feedback discussion of inhaled steroid use: its effect on adherence. *Annals of Allergy, Asthma and Immunology* 90:411–415.

Osborne RH, Spinks JM and Wicks IP (2004). Patient education and self-management programs in arthritis. *Medical Journal of Australia* 180:S23–S26.

http://www.mja.com.au/public/issues/180_05_010304/osb10565_fm.html

Parker R, Baker DW, Williams MV and Nurss JR (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine* 10:537–541.

Pinnock C (2004). PSA testing in general practice: Can we do more now? *Medical Journal of Australia* 180:379–381.

http://www.mja.com.au/public/issues/180_08_190404/pin10813_fm.html

Pinnock C, Weller D and Marshall V (1998). Self-reported prevalence of prostate specific antigen (PSA) testing in South Australia: a community study. *Medical Journal of Australia* 169:25–28. <http://www.mja.com.au/public/issues/jul6/pinnock/pinnock.html>

Poses RM, De Saintonge MC, McClish DK, Smith WR, Huber EC, Clemo LW, Schmitt BP, Alexander-Forti D, Racht EM, Colenda CC and Centor RM (1998). An international comparison of physicians' judgements of outcome rates of cardiac procedures and attitudes towards risk, uncertainty, justifiability, and regret. *Medical Decision Making* 18:131–140.

Rakow T (2001). Differences in belief about likely outcomes account for differences in doctors' treatment preferences: but what accounts for the differences in belief? *Quality in Health Care* 10: i44–i49.

Rees CE, Ford JE and Sheard CE (2002). Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. *Patient Education and Counseling* 47:273–275.

Roberts C (2004). 'Only connect': the centrality of doctor–patient relationships in primary care. *Family Practice* 21:232–233.

Roberts C, Sarangi S and Moss B (2004). Presentation of self and symptoms in primary care consultations involving patients from non-English speaking backgrounds. *Communication and Medicine* 1: 159–169.

Robinson A and Thomson R (2001). Variability in patient preferences for participating in medical decision making: implications for the use of decision support tools. *Quality in Health Care* 10:i34–i38.

Rowland-Morin PA and Carroll JG (1990). Verbal communication skills and patient satisfaction. A study of doctor–patient interviews. *Evaluation and the Health Professions* 13:168–185.

Royal Australasian College of Physicians (RACP) (2001). *An Introduction to Cultural Competency*. RACP (revised 2004).

Schapira MM and VanRuiswyk J (2000). The effect of an illustrated pamphlet decision-aid on the use of prostate cancer screening tests. *Journal of Family Practice* 49:418–424.

Schapira MM, Nattinger AB and McHorney CA (2001). Frequency or probability? A qualitative study of risk communication formats used in healthcare. *Medical Decision Making* 21:459–467.

Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, Palacios J, Sullivan GD and Bindman AB (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association* 288:475–482.

Sedgewick P and Hall A (2003). Teaching medical students and doctors how to communicate risk: combining the teaching of statistics with communication skills. *British Medical Journal* 327:694–695.

Slevin TJ, Donnelly N, Clarkson JP, English DR and Ward JE (1999). Prostate cancer testing: behaviour, motivation and attitudes among Western Australian men. *Medical Journal of Australia* 171:185–188.

Steginga SK (2003). How patients make decisions: the role of lay beliefs about health. Providing Informed Choice for Prostate Cancer Testing in General Practice, Australian Prostate Cancer Collaboration, Melbourne.

- Steginga SK, Occhipinti S, Gardiner RA, Yaxley J and Heathcote P (2002). Making decisions about treatment for localized prostate cancer. *BJU International* 89(3):255–260.
- Stevenson FA, Gerrett D, Rivers P and Wallace G (2000). GPs' recognition of, and response to, influences on patients' medicine taking: the implications for communication. *Family Practice* 17:119–123.
- Stewart M, Brown JB, Boon H, Galajda J, Meredith L and Sangster M (1999). Evidence on patient–doctor communication. *Cancer Prevention and Control* 3:25–30.
- Strull WM, Lo B and Charles G (1984). Do patients want to participate in medical decision making? *Journal of the American Medical Association* 252:2990–2994.
- Suarez-Almazor ME (2004). Patient physician communication. *Current Opinion in Rheumatology* 16:91–95.
- Taylor P (2005). Making decisions about mammography. *British Medical Journal* 330:915–916. <http://bmj.bmjournals.com/cgi/content/extract/330/7497/915>
- Teutsch C (2003). Patient–doctor communication. *The Medical Clinics of North America* 87:1115–1145.
- Thornton H (2003). Patients' understanding of risk. *British Medical Journal* 327:693–694.
- Tooth L, McKenna K, Maas F and McEniery P (1997). The effects of pre-coronary angioplasty education and counselling on patients and their spouses: a preliminary report. *Patient Education and Counseling* 32:185–196.
- Towle A and Godolphin W (1999). Framework for teaching and learning informed shared decision making. *British Medical Journal* 319:766–769.
- Vastag B (2004). Low health literacy called a major problem. *Journal of the American Medical Association* 291:2181–2182.
- Volk RJ, Cantor SB, Spann SJ, Cass AR, Cardenas MP and Warren MM (1997). Preferences of husbands and wives for prostate cancer screening. *Archives of Family Medicine* 6:72–76.
- Volk RJ, Spann SJ, Cass AR and Hawley ST (2003). Patient education for informed decision making about prostate cancer screening: a randomized controlled trial with 1-year follow up. *Annals of Family Medicine* 1:22–28.

- Ward JE, Hughes A-M, Hirst GHL and Winchester L (1997). Men's estimates of prostate cancer risk and self-reported rates of screening. *Medical Journal of Australia* 167:250–253.
<http://www.mja.com.au/public/issues/sep1/ward/ward.html>
- Wellard S, Lillibridge J, Beanland C and Lewis M (2003). Consumer participation in acute care settings: an Australian experience. *International Journal of Nursing Practice* 9:255–260.
- Weller D, Pinnock C, Silagy C, Hiller JE and Marshall VR (1998). Prostate cancer testing in SA men: influence of sociodemographic factors, health beliefs and LUTS. *Australian and New Zealand Journal of Public Health* 22:400–402.
- Weller D, May F, Rowett D, Esterman A, Pinnock C, Nicholson S, Doust J and Silagy C (2003). Promoting better use of the PSA test in general practice: randomized controlled trial of educational strategies based on outreach visits and mailout. *Family Practice* 20(6):655–661.
- Weston WW (2001). Informed and shared decision-making: the crux of patient-centred care. *Canadian Medical Association Journal* 165:438–439.
- Williams M, Baker DW, Parker RM and Nurss JR (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Archives of Internal Medicine* 158:166–172.
- Willis K and Baxter J (2003). Trusting technology: women aged 40–49 years participating in screening for breast cancer — an exploratory study. *Australian and New Zealand Journal of Public Health* 27:282–286.
- Wolf AM, Nasser JF, Wolf AM and Schorling JB (1996). The impact of informed consent on patient interest in prostate-specific antigen screening. *Archives of Internal Medicine* 156:1333–1336.
- Woloshin S, Schwartz LM and Ellner A (2003). Making sense of information on the web. *British Medical Journal* 327:695–696.
- Woolf SH, Krist AH, Johnson RE and Stenborg PS (2005). Unwanted control: how patients in the primary care setting decide about screening for prostate cancer. *Patient Education and Counseling* 56:116–124.
- Wright P, Belt S and John C (2004). Helping people assess the health risks from lifestyle choices: Comparing a computer decision aid with customized printed alternative. *Communication and Medicine* 1:183–192.

Appendix 1: Development process

This appendix describes:

- the rationale for developing the toolkit
- the process used to undertake the literature review on which the toolkit is based
- the process used to translate the findings of the literature review into the current toolkit.

RATIONALE

In 2004, the Health Advisory Committee (HAC) of the National Health and Medical Research Council (NHMRC) identified as a priority the development of a toolkit on communicating with healthcare consumers about the risks, benefits and outcomes of elective therapeutic and diagnostic interventions. The toolkit would extend advice in previous publications, such as:

- *Communicating with Patients: Advice for Medical Practitioners* (NHMRC 2004a)
- *General Guidelines for Medical Practitioners on Providing Information to Patients* (NHMRC 2004b)
- *10 Tips for Safer Health Care* (ACSQHC 2003).

The NHMRC established the Working Committee on Communicating the Risks, Benefits and Outcomes of Elective Therapeutic and Diagnostic Interventions between Consumers and Clinicians in July 2004. The aim of establishing the committee was to improve informed decision making by developing one or more toolkits aimed at healthcare consumers and healthcare professionals.

WORKING COMMITTEE TERMS OF REFERENCE

On behalf of the NHMRC Health Advisory Committee, the working committee will:

1. Conduct a literature review of the essential principles to be addressed when communicating the risks, benefits and outcomes of elective therapeutic and diagnostic interventions between consumers and clinicians, and the specific communication issues applicable to a diagnostic test (screening men by measuring prostate specific antigen [PSA] to detect early prostate cancer);

a surgical procedure (carotid endarterectomy for symptomatic carotid stenosis OR coronary angioplasty); and a drug treatment (glucocorticoids in patients with chronic medical conditions).

2. Develop toolkits for consumers (and their carers and families) and clinicians on communicating and understanding the risks, benefits and outcomes of elective therapeutic and diagnostic interventions, using the specific examples above to illustrate the generic issues. The toolkit contents will be determined by the literature review. They will improve informed decision making by including:

- tools that provide options for clinician/patient interactions (Emanuel EJ, Emanuel LL. Four models of the physician–patient relationship. *JAMA* 1992; 267:2221–2226)
- tools to recognise issues affecting and barriers to communication which mean that although different consumers and clinicians are presented with the same scientific data, the risks and benefits of interventions are perceived differently. These should include gender, age, socioeconomic influences, background and culture and the capacity to handle uncertainty, as well as ‘cognitive biases’ (eg ‘acceptable’ risks are those which are more familiar, seen as controllable by the consumer, to have immediate, rather than delayed benefits, and to be less readily recalled). (Greenhalgh T, Kostopoulou O, Harries C. Making decisions about benefits and harms of medicine. *BMJ* 2004;329:47–50)
- tools to recognise and address functional health literacy and numeracy
- tools to recognise the ‘weighting’ given by consumers to health-related matters compared to other competing issues affecting them
- tools to recognise and address the manner in which scientific data is ‘framed’ (eg mortality versus survival, absolute versus relative data, individualised versus group data)
- tools which outline the advantages and disadvantages of the type of communication channel (eg visual [graphs, pictures], print media, speech, multimedia), the degree of interactivity (eg decision aids), and the use of different language, including metaphors (Bedell SE et al. Words that harm, words that heal. *Arch Int Med* 2004; 164:1365–1367)
- tools which outline steps for discussing evidence (eg Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. *JAMA* 2004; 291:2359–2366)

- tools which assist clinicians and consumers to find further information, including decision aids relevant to specific interventions.
3. Identify target audiences.
 4. Develop effective implementation and dissemination strategies for the toolkits.
 5. Recommend evaluation strategies for the toolkits.
 6. Undertake public consultation to improve useability.
 7. Present the draft toolkits to HAC.

LITERATURE REVIEW

The committee commissioned a systematic literature review to explore the general issues and determine the evidence base for communicating the risks, benefits and outcomes of elective therapeutic and diagnostic interventions with healthcare consumers.

The review was undertaken by Dr Chris Peterson and Associate Professor Greg Murphy of La Trobe University, and Professor Brian McAvoy and Dr Faline Howes of the National Cancer Control Initiative.

OBJECTIVES OF THE REVIEW

The objectives of the literature review were to identify and collect relevant information in relation to:

- issues to be addressed when communicating the risks, benefits and outcomes of elective therapeutic and diagnostic interventions between consumers and clinicians, such as:
 - the specific channels of communication (including oral, print media, multimedia, decision aids and models, but excluding nonverbal communication)
 - the barriers to exchange and utilisation of information, including the importance of cultural, socioeconomic, language and linguistic considerations for effective communication
- the efficacy and effectiveness of different communication channels, content and styles for communicating the risks, benefits and outcomes of elective therapeutic and diagnostic interventions between consumers and clinicians in achieving better comprehension and satisfaction, and other relevant outcomes

- the specific communication issues, including clinician and consumer material, applicable to the following cases:
 - a diagnostic test (screening men using prostate specific antigen [PSA] to detect early prostate cancer)
 - a surgical procedure (coronary angioplasty)
 - a drug treatment (glucocorticoids in patients with chronic medical conditions).

REVIEW CRITERIA

The review team used the following criteria for considering whether to include studies in the review.

Types of studies

All study designs were examined for inclusion, including other systematic reviews and meta-analyses, randomised controlled studies, observational studies and qualitative studies. Where possible, a hierarchy of evidence was applied in accordance with the NHMRC guidelines *How to Use the Evidence: Assessment and Application of Scientific Evidence* (NHMRC 2000).

Types of participants

Only studies involving people over the age of 15 who were making decisions about elective therapeutic and diagnostic interventions for themselves were included.

Types of intervention

Studies considered were those with interventions designed to help people make specific and deliberate choices among options by providing information on the risks, benefits and outcomes relevant to a person's health status. These interventions included communicating via oral means, print media, multimedia, and decision aids and models.

Where possible, studies were included that examined the influence of socioeconomic status, gender, culturally and linguistically diverse backgrounds, and the perceptions of clinicians and consumers involved in the information transfer process. Selected studies that explored the theoretical context within which information is transferred and provided holistic assessments of both healthcare consumer and professional variables were examined.

Studies were excluded if the intervention focused on nonverbal communication, decisions about lifestyle changes, clinical trial entry, or general approaches to treatment if the person

should become unable to participate in the future, including end-of-life decisions, education programs not geared to a specific decision, and interventions designed to promote adherence to a recommended option.

Types of outcome measures

A broad range of positive and negative effects on the decision-making process and on the outcomes of decisions were considered. Outcomes included:

- communication between practitioners and consumers
- knowledge; realistic expectations
- agreement between personal values for outcomes and choice
- implementation of preferred choice; satisfaction with the decision, the decision-making process, and the decision support provided
- the actual choice made
- health-related quality of life
- adherence to the chosen option
- resource use
- emotional distress, anxiety, depression and regret
- barriers to, as well as facilitators of, the exchange and use of information (for example cultural, socioeconomic and language considerations).

Limits

Studies were limited to those published in the English language. The date restrictions applied were those of the databases searched.

SEARCH STRATEGY

The review used a two-part search strategy. An initial search strategy was designed to cover the objectives set out above. This search uncovered a large number of potentially relevant reviews, and it was agreed with the committee that these reviews would provide the main source of information for this review. Additional search strategies were designed to cover the three specific issues that were to be used as illustrative examples (PSA screening, coronary angioplasty and glucocorticoids).

Search strategy for identification of studies

In the initial search strategy, the following electronic databases were searched:

- MEDLINE (1966 to October 2004) and MEDLINE In-Process & Other Non-Indexed Citations (November 2004)
- PsycINFO (1985 to October 2004)
- Cochrane Database of Systematic Reviews (October 2004) and Cochrane Consumers and Communication Review Group Specialised Register (October 2004)
- *Health Technology Assessment* Database (October 2004)
- Centre for Reviews and Dissemination publications (October 2004)
- National Health and Medical Research Council publications (October 2004).

The MEDLINE and PsycINFO search strategies were of the general structure 'Intervention synonyms' AND 'Outcome synonyms'. The search strategy used with MEDLINE was translated into comparable strategies for use in the other databases (see Table A1 for search terms used). Bibliographies of studies located in the electronic databases were examined and a small number of author searches were conducted. A wide range of websites were searched, including prostate cancer, linguistic, consumer, clinical and government websites. In addition, key individuals and organisations were contacted, including cancer, heart and consumer groups.

Table A1 Database and search history

No.	Search history	Results (no. of papers)
Database: Ovid MEDLINE (1966 to October Week 4 2004)		
1	*Patient Education/ or *Health Education/ or *Decision Support System, Clinical/ or *Decision Support Techniques/ or *Truth Disclosure/ or *Disclosure/ or *Risk Assessment/ or *Risk Factors/ or *Physician-Patient Relations/ or *Choice Behavior/ or *Decision Making/ or *Communication/ or *Communication Barriers/ or *Informed Consent/ or exp Consumer Participation/ or Patient Participation/	117479
2	(information\$ adj3 (oral or written or write or card\$ or helpcard\$ or leaflet\$ or script\$ or booklet\$ or guidebook\$ or guideline\$ or checklist\$ or check list\$ or telephone\$ or phone\$ or video\$ or multimedia\$ or decision aid\$ or decision model\$)).tw.	5989

No.	Search history	Results (no. of papers)
3	1 or 2	122425
4	*Patient Acceptance of Health Care/ or *Health Knowledge, Attitudes, Practice/ or *Patient Satisfaction/ or exp Consumer Satisfaction/ or *Treatment Outcome/ or *Treatment Refusal/	59320
5	3 and 4	6908
6	limit 5 to (human and English language)	5961
7	limit 6 to (comment or letter)	326
8	6 not 7	5635
9	animal/	3730694
10	8 not 9	5613
11	(polymorphism\$ or allele\$ or child or children or emergency or critically ill).tw.	661389
12	10 not 11	5132
13	remove duplicates from 12	5024
14	limit 13 to 'review articles'	312
15	meta-analysis.ti.	5162
16	13 and 15	1
17	14 or 16	313
Ovid MEDLINE In-Process & Other Non-Indexed Citations (November 08, 2004)		
1	(Patient Education or Health Education or Decision Support System or Decision Support Techniques or Truth Disclosure or Disclosure or Risk Assessment or Risk Factors or Physician-Patient Relations or Choice Behavior or Decision Making or Communication or Communication Barriers or Informed Consent or Consumer Participation or patient participation).mp. [mp=title, original title, abstract, name of substance]	6585
2	(information\$ adj3 (oral or written or write or card\$ or helpcard\$ or leaflet\$ or script\$ or booklet\$ or guidebook\$ or guideline\$ or checklist\$ or check list\$ or telephone\$ or phone\$ or video\$ or multimedia\$ or decision aid\$ or decision model\$)).tw.	189
3	1 or 2	6734
4	(Patient Acceptance of Health Care or Health Knowledge, Attitudes, Practice or Patient Satisfaction or Consumer Satisfaction or Treatment Outcome or Treatment Refusal).mp. [mp=title, original title, abstract, name of substance]	487
5	3 and 4	52
6	limit 5 to English language	48
7	limit 6 to 'review articles'	0

No.	Search history	Results (no. of papers)
Ovid PsycINFO (1985 to October Week 4 2004)		
1	*Client Education/ or *Health Education/ or *Decision Support Systems/ or *Risk Analysis/ or *Risk Factors/ or *Choice Behavior/ or *Decision Making/ or *Communication/ or *Informed Consent/	30009
2	(information\$ adj3 (oral or written or write or card\$ or helpcard\$ or leaflet\$ or script\$ or booklet\$ or guidebook\$ or guideline\$ or checklist\$ or check list\$ or telephone\$ or phone\$ or video\$ or multimedia\$ or decision aid\$ or decision model\$)).tw.	1992
3	1 or 2	31763
4	*Treatment Compliance/ or exp Consumer Satisfaction/ or *Treatment Outcomes/ or *Treatment Refusal/ or *Client Attitudes/ or *Health Attitudes/ or *Health Knowledge/	21957
5	3 and 4	1186
6	limit 5 to (human and English language)	1126
7	remove duplicates from 6	1113
8	(polymorphism\$ or allele\$ or child or children or emergency or critically ill).tw.	177903
9	7 not 8	1007
10	(review or meta-analysis).ti.	15709
11	9 and 10	11

Sociological Abstracts (1963 to present), and the Joanna Briggs Institute database²⁶ were also searched. Two linguistic journals were handsearched: *Health, Risk and Society* (Vol. 2, No 1, 2000 to Vol 6, No 3, 2004) and *Communication and Medicine* (Vol 1, No 1, 2004).

Literature for the three specific examples was sought when screening titles in the search strategies described above. Searches using specific MeSH and key words in MEDLINE were conducted and key individuals were contacted.

CATEGORIES OF LITERATURE RETRIEVED

The literature retrieved fell within three general categories:

- An extensive literature on the benefits of improved communication, some of the pitfalls involved, and the need for improving communication practice. This literature has been covered extensively and was mentioned only briefly in the review, to demonstrate the agreed benefits of improved communication.

²⁶ <http://www.joannabriggs.edu.au>

- Literature focusing on the cause of poor communication, and identifying particular practices shown to improve communication. Such publications more commonly focus on the message senders (healthcare professionals) than on the receiving population (healthcare consumers).
- A smaller body of literature focusing on the theories of communication and how these may be applied to communication between healthcare consumers and healthcare professionals.

The literature could also be classified as either clinical or sociological. Studies covering clinical aspects related to how clinical and technical information can be conveyed to consumers in ways that allow maximum processing of the information. The reviewers noted that although the clinical aspect is important, it tends to neglect:

- the many issues involved in the transmission and reception of information
- the political context and potential political agenda of the consumer or the professional
- social and cultural contexts, emotional and psychosocial processes and the effect of status differences between the person sending the message and the person receiving it.

Thus, the sociological perspective is required, to provide a sense of meaning and context (political, status, social or cultural) into the interaction between consumer and professional.

Although much of the literature retrieved in the review fell within the clinical category, the reviewers also considered sociological studies, to instil more meaning into the context of the medical communication of information.

The reviewers recognised that addressing Aboriginal and Torres Strait Islander issues in a substantial manner was beyond the remit of the literature review, but acknowledged the importance of communication with Aboriginal and Torres Strait Islander peoples.

DEVELOPMENT OF THE TOOLKIT

The findings of the literature review were used to develop the five principles that form the basis of the toolkit. The papers retrieved in the review were then used to develop the text of the toolkit. Additional studies were identified by the committee and by the public consultation process.

Given that each principle was based on the findings of multiple studies, it was not feasible to give each statement a reference. Instead, the published studies from which the principle was derived are listed at the end of the principle. As explained in the *Introduction*, the criteria developed by the NHMRC for assessing the level and quality of research evidence could not be readily applied here because many of the studies used in preparing the toolkit were qualitative. However, systematic reviews are identified as such, and the examples given in each principle describe individual studies in sufficient detail to provide readers with an indication of the strength of the evidence and its applicability to the Australian situation.

Appendix 2:

Publication, dissemination and implementation

PUBLICATION FORMAT

The toolkit has been professionally designed, and is available as:

- a conventional hardcopy printed document
- web-based document

DISSEMINATION AND IMPLEMENTATION

The committee has identified a range of stakeholders for the toolkit:

- healthcare consumers and the various groups representing them
- healthcare professionals and the various groups representing them
- groups and organisations developing training materials for groups such as:
 - healthcare consumer groups, carer organisations and support groups
 - healthcare professionals (nurses, doctors, dentists, physiotherapists, etc) at undergraduate and postgraduate levels, including those undergoing training and professional development
 - overseas-trained healthcare professionals (for example, for use by certification boards)
 - professional development (for example, for professional societies, group practices, area health services and Divisions of General Practice)
 - senior staff within health services
 - medical defence organisations
 - school or college students in years 11 and 12 (as part of a module about health)
 - University of the Third Age (U3A).

Potential users of the toolkit will learn of publication of the toolkit through other avenues; for example:

- the NHMRC website
- the websites of consumer and professional healthcare organisations

- publications for consumers
- journals for professionals
- radio interviews by representatives of the NHMRC.

To ensure implementation of the principles on which the toolkit is based, the committee suggests that the toolkit be used as a training resource at all levels of training of healthcare professionals (undergraduate, postgraduate and professional development), in training courses developed by healthcare consumer groups, and in other resources aimed directly at healthcare consumers and healthcare professionals.

Appendix 3

Working committee

Members of the NHMRC Working Committee on Communicating the Risks, Benefits and Outcomes of Elective Therapeutic and Diagnostic Interventions between Consumers and Clinicians, the secretariat and the technical writers are listed below.

WORKING COMMITTEE MEMBERS

Dr Peter Greenberg (Chair)	Consultant Physician Royal Melbourne Hospital <i>Member of Health Advisory Committee</i>
Dr Rosemary Aldrich	Public Health Physician, Newcastle, New South Wales <i>Member of Health Advisory Committee</i>
A/Professor Rachelle Buchbinder	Rheumatologist and Clinical Epidemiologist Cabrini Hospital and Monash University, Victoria
Dr Rosemary Clerehan	Head, Language and Learning Services Unit, Centre for Learning and Teaching Support, Monash University
Dr Peter Joseph	General Practitioner, South Australia <i>Member of Health Advisory Committee</i>
Professor Judy Lumby	Executive Director, The College of Nursing, New South Wales
Dr Christine Walker	Chief Executive Officer, Chronic Illness Alliance Inc, Victoria
Ms Ros Wood	Consumer representative, Tasmania

NHMRC SECRETARIAT

Ms Stephanie Gates

TECHNICAL WRITERS

Dr Hilary Cadman, Biotext Pty Ltd, Canberra

Dr Janet Salisbury, Biotext Pty Ltd, Canberra

Appendix 4

Individuals and organisations submitting comments

The following individuals or organisations submitted comments on the draft publication when it was released for publication consultation in August 2005.

Liz Abell, Manager, Community Involvement & Support Programs
Australian Health Ethics Committee, National Health and Medical
Research Council

Professor Alexandra Barratt, Associate Professor of Epidemiology,
Sydney Health Decision Group, Faculty of Medicine, University of
Sydney

Marilyn Beaumont, Executive Director, Women's Health Victoria

Mark Bebbington, Policy and International Manager, Australian
Federation of AIDS Organisations Inc.

Jim Birch, Chief Executive, Department of Health, Government of
South Australia

Dr Jennifer Bowers, Chief Executive Officer, Carers Australia

Bob Bradford, Executive Officer, Medical Board of the ACT

Dr Caroline Brand, Director, Clinical Epidemiology and Health
Services Evaluation Unit

Dr Kerry Breen

Hazel Bridgett, Community & Health Officer, Lismore Legacy Club

Margaret Brown, Chair, Health Consumers of Rural and Remote
Australia Inc.

Dr Jeff Brownscombe, Public Health Registrar, Department of
Health and Community Services, Northern Territory Government

Rosemary Bryant, Executive Director, Royal College of Nursing,
Australia

Dr Heather Buchan, Chief Executive Officer, National Institute of
Clinical Studies

Noelene Burt, Chairperson, Wollongong Health Consumers

Barry Cahill, Chief Executive Officer, Continence Foundation of
Australia

Dermot Casey, Executive Director, Office of the Safety and Quality
Council, Australian Council for Safety and Quality in Health Care

Martina Chippindall, Adult Health Program Officer, Practice
Support, Perth and Hills Division of General Practice

Sally Crossing, Chair, Breast Cancer Action Group NSW
Incorporated

Dr Leela de Mel, Executive Director, Office of Multicultural Interests, Department of the Premier and Cabinet, Government of Western Australia

Maria de Silva, Committee member, Ethnic Communities Council of WA

Gary Disher, Director, Policy and Communications, The Royal Australasian College of Physicians

Dr David Dumbrell, A/g Assistant Secretary, Strategic Planning Branch, Population Health Division, Australian Government, Department of Health and Ageing

Anne Eayrs, National Policy Officer, Alzheimer's Australia

Peter Edwards, Chair, Northern Illawarra Health Watch

A/Prof Frank Fisher, Director, Graduate School of Environmental Science, Monash University

Professor Alan Coates, Chief Executive Officer, The Cancer Council Australia

R. L. Guest, Chief Executive Officer, The Royal Australian and New Zealand College of Ophthalmologists

Jane Halton, Chair, National Aboriginal and Torres Strait Islander Health Council, Australian Government

Professor Richard Henry, A/g Dean, Faculty of Medicine, The University of New South Wales

Professor David J Hill, Director, The Cancer Council Victoria

Dr Sophie Hill, School of Public Health, La Trobe University

Allan Hunter, Deputy Chief Executive Officer, United Medical Protection Ltd and Australasian Medical Insurance Limited

Rosemary Huxtable, A/g First Assistant Secretary, Acute Care Division, Australian Government, Department of Health and Ageing

Professor Joseph Ibrahim, Director, Aged & Palliative Care Services, Mt Eliza Centre

Jill Iliffe, Federal Secretary, Australian Nursing Federation

Judy Irwig

Professor Michael Kidd, President, Royal Australian College of General Practitioners

Michele Kosky, Executive Director, Health Consumers' Council WA Inc.

Professor Louis Landau, Chair, Postgraduate Medical Council of WA

Dr Andrew Langley, Public Health Physician, Central Zone Public Health Network — Sunshine Coast

Dr Brian Lloyd, Chief Medical Officer, Department of Health, Government of Western Australia

Harry Lovelock, Director, Policy Unit, Royal Australian and New Zealand College of Psychiatrists

Michael Lowe, A/g Clinical Dean, Flinders University Northern Territory Clinical School

Abd Malak AM, Director, Diversity Health Institute

Angela Manson, Director, Multicultural Health Services, Sydney South West Area Health Service — Eastern Zone

Dr Raymond Martyres, Melbourne Division of General Practice

Mary Mathews, Chief Executive Officer, Monash Division of General Practice

Professor Brian R. McAvoy, Deputy Director, National Cancer Control Initiative

Richard McCluskey, President, Heart Support — Australia

Lee McGovern, Senior Allied Health Adviser, Professional Services Advice Branch, Department of Health and Human Services, Government of Tasmania

Narelle McInnes, Program Officer, Population Health, Capricornia Division of General Practice

John Mendoza, Chief Executive Officer, Mental Health Council of Australia

Phoebe Mwaniki, Policy Adviser, Australian Divisions of General Practice

John O'Dea, Director, Medical Practice Department, Australian Medical Association Limited

Cheryl M Pearce

Carole Pinnock, Australian Prostate Cancer Collaboration Education Committee

Gordon Renouf, General Manager Policy & Campaigns, Australian Consumers' Association

Panayiota Romios, A/g Chief Executive Officer, Health Issues Centre, La Trobe University

Dr Ian Scott, Director, Clinical Services Evaluation Unit, Internal Medicine Society of Australia and New Zealand

Jim Simpson, Senior Advocate, NSW Council for Intellectual Disability

Terri Smith, National Programs Manager, Breast Cancer Network
Australia

Suzanne Steginga, Director, Community Services, Queensland
Cancer Fund

Gordon Storey & Karenza Louis-Smith, The Association of
Participating Service Users

Peter Todaro, Director, NSW Multicultural *Health Communication*
Service, South Eastern Sydney and Illawarra Area Health Service

Dr Sally Torr, South Eastern Sydney and Illawara Health Service

Dr Hubert van Doorn, General Practitioner, East Brunswick Medical
Centre

Marian Vickers, Convenor, DES Action Australia

Dr Tamsin Waterhouse, Deputy Chief Executive Officer, The Royal
College of Pathologists of Australia

Donna Waters, Research Manager, The College of Nursing

Dr Lynn Weekes, Chief Executive Officer, National Prescribing
Service

Jane Widdison, Manager, Performance Unit, Western Health

Jennifer Williams, Chief Executive, Bayside Health

Debbie Zajacek, Executive Assistant, Southern Queensland Rural
Division of General Practice Association Inc.

The National Health and Medical Research Council

The National Health and Medical Research Council (NHMRC) was established in 1936 and is now a statutory body within the portfolio of the Australian Government Minister for Health and Ageing, operating under the *National Health and Medical Research Council Act 1992* (NHMRC Act). The NHMRC advises the Australian community and the Australian Government, and State and Territory governments on standards of individual and public health, and supports research to improve those standards.

The NHMRC Act provides four statutory obligations:

- to raise the standard of individual and public health throughout Australia;
- to foster development of consistent health standards between the states and territories;
- to foster medical research and training and public health research and training throughout Australia; and
- to foster consideration of ethical issues relating to health.

The NHMRC also has statutory obligations under the *Prohibition of Human Cloning Act 2002* (PHC Act) and the *Research Involving Human Embryos Act 2002* (RIHE Act).

The activities of the NHMRC translate into four major outputs: health and medical research; health policy and advice; health ethics; and the regulation of research involving donated IVF embryos, including monitoring compliance with the ban on human cloning and certain other activities.

A regular publishing program ensures that Council's recommendations are widely available to governments, the community, scientific, industrial and education groups. The Council publishes in the following areas:

- Aboriginal and Torres Strait Islander Health
- Aged Care
- Blood and Blood Products
- Cancer
- Cardiovascular Health
- Child Health
- Clinical Practice Guidelines – Standards for Developers – Topics
- Communicable Diseases, Vaccinations and Infection Control
- Diabetes
- Drug and Substance Abuse
- Environmental Health
- Ethics in Research–Animal
- Ethics in Research–Human
- Genetics and Gene Technology
- Health Procedures
- Health Promotion
- Human Cloning and Embryo Research
- Indigenous Health
- Injury including Sports Injury
- Men's Health
- Mental Health
- Musculoskeletal
- NHMRC Corporate documents
- NHMRC Session Reports
- Nutrition and Diet
- Oral Health
- Organ Donation
- Poisons, Chemicals and Radiation Health
- Research
- Women's Health

NHMRC publications contact:

Email: nhmrc.publications@nhmrc.gov.au
Internet: <http://www.nhmrc.gov.au>
Free Call: 13 000 NHMRC (13 000 64672)
or phone 02 6217 9000

To Order Publications:

National Mailing and Marketing
PO Box 7077
Canberra BC 2610
Email: nmm@nationalmailing.com.au
Phone: (02) 6269 1000
Fax: (02) 6260 2770