



Australian Government

National Health and Medical Research Council

General Guidelines

for Medical Practitioners on
Providing Information to Patients



INVESTING IN AUSTRALIA'S HEALTH





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Providing Information to Patients

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To obtain details regarding NHMRC publications contact:

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Typeset by WhiteFox Communication
P. 0409 659 810 E. lindsay@whitefox.com.au
www.whitefox.com.au

PREFACE

This document *General Guidelines for Medical Practitioners on Providing Information to Patients* (hereafter referred to as the *General Guidelines*) was originally issued in 1993 following the publication of a report by the Australian, Victorian and New South Wales Law Reform Commissions on the issue of informed consent. NHMRC policy now requires that its documents are reviewed five years after publication to ensure that they remain relevant and up to date. In order to review the 1993 *General Guidelines*, NHMRC conducted a public consultation on the document from July to August 2002. The Australian Health Ethics Committee (AHEC), a principal committee of the NHMRC, then formed a working group to consider the submissions.

The working group concluded that the 1993 *General Guidelines* remains a valuable statement of what information needs to be exchanged between patients and doctors, and why. The working group also agreed that despite the existence of the 1993 *General Guidelines*, and other documents providing information on the ethical and legal requirements for informed consent, many difficulties remain. Problems around providing information to patients relate not only to what information is provided to patients, but also to how the communication of that information occurs. The working group and AHEC therefore concluded that an additional document should focus on the importance of good communication between doctors and patients and highlight good communication practices.

The working group went on to develop the document *Communicating with Patients: Advice for Medical Practitioners* as a companion document to the *General Guidelines*. Council endorsed *Communicating with Patients: Advice for Medical Practitioners* and re-endorsed the *General Guidelines* at its 152nd Session on 18 March 2004. These publications are now published as complementary documents to assist medical practitioners, medical students and the community, to utilise effective communication methods in the exchange of appropriate information between patients and doctors.

I congratulate AHEC and members of the working group for their efforts in producing *Communicating with Patients: Advice for Medical Practitioners* and pay tribute to the previous NHMRC working group responsible for the *General Guidelines* which have stood the test of time.



Professor John Shine AO
Chair, National Health and Medical Research Council
April 2004.

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A FOREWORD

Following a recommendation by the Australian, Victorian and New South Wales Law Reform Commissions (see Appendix), the National Health and Medical Research Council established a Working Party to formulate guidelines on the provision of information to patients by medical practitioners.

There is a community recognition that patients are entitled to make their own decisions about their medical treatment. These decisions will need to be based on information and advice given by the doctor.

This document provides general guidelines outlining information which should normally be given to patients to help them make informed decisions about proposed investigations or treatment. No set of guidelines can cover all the circumstances surrounding relationships between patients and doctors, and these guidelines do not attempt to describe the quality of relationship which should be developed.

The issues discussed will affect everyone at some time in their lives, and it is proposed that the document be circulated widely among health professionals and the general community.

The legal duty of a doctor to give information about medical interventions, especially about material risks, was emphasised by the High Court of Australia in November 1992.

While it is recognised that these guidelines might be consulted in legal proceedings, it is not their purpose to set mandatory standards of behaviour in giving information. Rather it is to foster better communication between doctor and patient, so that patients are able, with their doctors, to make the best decisions about their medical care.

Richard Smallwood
Chairman, Health Care Committee¹
National Health and Medical Research Council
June 1993.

¹ Please note that the following information was relevant as at the time of first endorsement:

The *General Guidelines for Medical Practitioners on Providing Information to Patients* was prepared by a Working Party of the Health Care Committee. It was endorsed by the Health Care Committee in April 1993 and by the NHMRC at its 115th Session in June 1993.

The Health Care Committee, was at that time, a principal committee of the NHMRC tasked with inquiries into and advising on matters relating to the provision of health services and the merits of methods of disease prevention, diagnosis and treatment.

MEMBERSHIP

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Dr J Vallentine	Physician, nominee of the Medical Defence Union
Professor L Waller, AO	Sir Leo Cussen Chair of Law, Law Faculty, Monash University, Melbourne, nominee of the Victorian Law Reform Commission

B INTRODUCTION

These guidelines are intended to enhance doctor-patient communication. They reflect good medical practice and should encourage co-operation and improved health outcomes. They cover:

- the type of information which should be given to patients;
- the particular need to give information about potential risks, as well as benefits, of a proposed medical intervention;
- the manner in which information should be given; and
- circumstances where withholding information may be justified.

The community recognises that patients are entitled to make their own decisions. In order to do so, they must have enough information about their condition, investigation options, treatment options, benefits, possible adverse effects of investigations or treatment, and the likely result if treatment is not undertaken. It is not possible however, to provide complete information or to predict outcomes or assess risks with certainty, and patients need to be aware of this uncertainty.

An open exchange between doctors and patients is crucial. Each brings to the consultation different information, options and understanding which are important for making decisions and achieving the patient's well-being. Allowing opportunity for discussion may be as important for patients as giving and receiving information.

Consultations between doctors and patients take place in a wide variety of circumstances which are not always ideal. Often patients are sick or injured and they and their relatives may be anxious. For these and other reasons, patients may have difficulty comprehending the information given by doctors. It is important that doctors use language which is simple and free of medical jargon, and that they try to ensure that the information is understood and retained.

Many doctor-patient contacts are of a relatively straightforward and minor nature. In practice this will usually mean that the exchange of needed information can be accomplished simply and briefly, while the spirit and intent of the guidelines are observed.²

Careful and conscientious adherence to the guidelines may on occasion demand extra time (for example, to ensure that key information has been grasped and retained) with attendant cost implications.³

The guidelines reflect the common law right of legally competent patients to make their own decisions about medical treatment, and their right to grant, withhold or withdraw consent before or during examination or treatment. The guidelines do not change the law, nor do they set a mandatory standard. Rather, they reflect the doctor's

² Common sense indicates that, for many proposed investigations or treatments, it is not necessary for doctor and patient to enter into prolonged discussions about the pros and cons of the intervention, eg. treatment of a minor cut.

³ For example, if a patient is advised that he or she needs an organ transplant, an extended period of consultation and counselling is necessary.

existing common law responsibility always to take reasonable care.⁴ In appropriate circumstances, divergence from the guidelines would not inevitably be regarded as negligent or unprofessional behaviour. The guidelines may be consulted in disciplinary or civil proceedings in deciding whether the doctor has behaved reasonably in giving information, although ultimately it will be the role of the court to decide the reasonableness of a doctor's behaviour in a given case.

⁴ The word reasonable used here and later in the document, is not readily defined, other than in the circumstances of a particular situation.

C PRINCIPLES

The guidelines are based on the general principle that patients are entitled to make their own decisions about medical treatments or procedures and should be given adequate information on which to base those decisions.

Information should be provided in a form and manner which help patients understand the problem and treatment options available, and which are appropriate to the patient's circumstances, personality, expectations, fears, beliefs, values and cultural background.

Doctors should give advice. There should be no coercion, and the patient is free to accept or reject the advice.

Patients should be encouraged to make their own decisions.

Patients should be frank and honest in giving information about their health, and doctors should encourage them to be so.

D GENERAL GUIDELINES ON INFORMATION

INFORMATION TO BE GIVEN

Doctors should normally discuss the following information with their patients:⁵

- the possible or likely nature of the illness or disease;
- the proposed approach to investigation, diagnosis and treatment:
 - what the proposed approach entails
 - the expected benefits
 - common side effects and material risks of any intervention⁶
 - whether the intervention is conventional or experimental
 - who will undertake the intervention
- other options for investigation, diagnosis and treatment;
- the degree of uncertainty of any diagnosis arrived at;
- the degree of uncertainty about the therapeutic outcome;
- the likely consequences of not choosing the proposed diagnostic procedure or treatment, or of not having any procedure or treatment at all;
- any significant long term physical, emotional, mental, social, sexual, or other outcome which may be associated with a proposed intervention;
- the time involved; and
- the costs involved, including out of pocket costs.

I INFORMING PATIENTS OF RISKS

Doctors should give information about the risks of any intervention, especially those that are likely to influence the patient's decisions. Known risks should be disclosed when an adverse outcome is common even though the detriment is slight, or when an adverse outcome is severe even though its occurrence is rare. A doctor's judgement about how to convey risks will be influenced by:

- the seriousness of the patient's condition; for example, the manner of giving information might need to be modified if the patient were too ill or badly injured to digest a detailed explanation;
- the nature of the intervention; for example, whether it is complex or straightforward, or whether it is necessary or purely discretionary. Complex interventions require more information, as do interventions where the patient has no illness;⁷
- the likelihood of harm and the degree of possible harm more information is required the greater the risk of harm and the more serious it is likely to be;

⁵ It will be evident that this detailed check list is inappropriate for minor interventions, and that even for major interventions, it may be unnecessarily elaborate, since some matters will be self-evident. Nonetheless it provides the basis for discussion with patients of proposed approaches to investigation and treatment.

⁶ In law, a risk is material if, in the circumstances of the particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it. Alternatively, a risk is material if the doctor is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it.

⁷ For example, the variety of information the patient needs about the risks and consequences of transplanting organs is much greater than in many more familiar procedures; similarly, in purely elective cosmetic surgery, any risk of scarring or unexpected aesthetic effects should be canvassed.

- the questions the patient asks; when giving information, doctors should encourage the patient to ask questions and should answer them as fully as possible. Such questions will help the doctor to find out what is important to the patient;
- the patient's temperament, attitude and level of understanding; every patient is entitled to information, but these characteristics may provide guidance to the form it takes; and
- current accepted medical practice.⁸

2 PRESENTING INFORMATION

The way the doctor gives information should help a patient understand the illness, management options, and the reasons for any intervention. It may sometimes be helpful to convey information in more than one session. The doctor should:

- communicate information and opinions in a form the patient should be able to understand;
- allow the patient sufficient time to make a decision. The patient should be encouraged to reflect on opinions, ask more questions, consult with the family, a friend or advisor. The patient should be assisted in seeking other medical opinion where this is requested;
- repeat key information to help the patient understand and remember it;
- give written information or use diagrams, where appropriate, in addition to talking to the patient;
- pay careful attention to the patient's responses to help identify what has or has not been understood; and
- use a competent interpreter when the patient is not fluent in English.⁹

3 WITHHOLDING INFORMATION

Information should be withheld in very limited circumstances only:

- if the doctor judges on reasonable grounds that the patient's physical or mental health might be seriously harmed by the information;¹⁰ or
- if the patient expressly directs the doctor to make the decisions, and does not want the offered information. Even in this case, the doctor should give the patient basic information about the illness and the proposed intervention.¹¹

4 EMERGENCIES

In an emergency, when immediate intervention is necessary to preserve life or prevent serious harm, it may not be possible to provide information.

⁸ In judging what to discuss, a doctor may consider the usual professional practice in the giving of information in a particular situation, but that is not conclusive. The doctor should take into account all of the circumstances in relation to the particular patient.

⁹ Preferably, the person acting as interpreter should be a trained medical interpreter and not a family member.

¹⁰ It is not appropriate to withhold information because the patient might be disconcerted or dismayed, or because the doctor finds the giving of the particular information unpalatable.

¹¹ The doctor must try to ensure that the patient has sufficient information and understanding to be able to waive his or her right to be informed and still to give valid consent.

E APPENDIX

BACKGROUND

In June 1989, the Australian, Victorian and New South Wales Law Reform Commissions published a report entitled 'Informed Decisions about Medical Procedures'. The Victorian Law Reform Commission had earlier begun an inquiry into informed decision making about medical interventions because of the growing recognition that patients should have more information than they had customarily been given to allow them to make decisions about their treatment, and because of a lack of clarity in the law concerning information which should be given by doctors to patients.

In 1986 to 1987 the Victorian Law Reform Commission had conducted empirical studies examining doctors' attitudes to, and practices in, giving information to patients, and into patients' experiences and expectations in receiving information from doctors. It was concluded that doctors were giving patients less information than they wanted, and on occasion less than was required to fulfil the common law standard of reasonable care. It was felt that an attitude prevalent among doctors, that the patient's best interests were served if doctors decided what information to give and what treatment was best, needed to change.

In their June 1989 report, the Law Reform Commissions recommended that the National Health and Medical Research Council formulate guidelines for the medical profession concerning the provision of information to patients about proposed treatment and procedures.

The Commissions rejected the notion that the common law standard of reasonable care concerning the provision of information to patients should be replaced by a statutory standard. It was considered that the common law provided a satisfactory general standard, and that, while more specific directions to doctors on the provision of information would be worth while, legislation was an impractical way to provide them. Legislation was too rigid and incapable of covering the wide range of situations which might arise. Guidelines provided greater flexibility, and might include examples to help illustrate general statements.

The report envisaged that these guidelines would be widely used. They were to be available to all medical practitioners and other health professionals, and incorporated into undergraduate education, quality assurance and peer review programs, and hospital accreditation reviews, as well as patient education and self-help programs. Such wide dissemination was seen as important if the guidelines were to influence professional practice and community understanding.

In January 1991, the National Health and Medical Research Council established a working party comprising consumers and health and legal professionals to formulate guidelines.

In October 1991, a preliminary discussion paper entitled 'General Guidelines for Medical Practitioners on Providing Information to Patients' was circulated widely to consumer

groups, health and legal professionals, health organisations and government, to allow public consultation and to promote broad public debate. Over 150 written submissions were received, the great majority of which supported the development of the Guidelines.

With the benefit of extensive public comment, the Guidelines were revised and submitted to Council at its meeting of June 1993, where they were adopted and approved for general circulation.

