



**A tool for health care improvement:
Comment on the Draft National Patient
Charter of Rights**

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Introduction

The Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) seeks to promote a just and democratic society by making strategic interventions on public interest issues.

PIAC is an independent, non-profit law and policy organisation that identifies public interest issues and works co-operatively with other organisations to advocate for individuals and groups affected.

In making strategic interventions on public interest issues PIAC seeks to:

- expose unjust or unsafe practices, deficient laws or policies;
- promote accountable, transparent and responsive government;
- encourage, influence and inform public debate;
- promote the development of law—both statutory and common—that reflects the public interest; and
- develop community organisations to pursue the interests of the communities they represent.

Established in July 1982 as an initiative of the Law Foundation of New South Wales, with support from the NSW Legal Aid Commission, PIAC was the first, and remains the only, broadly based public interest legal centre in Australia. Financial support for PIAC comes primarily from the NSW Public Purpose Fund and the Commonwealth and State Community Legal Services Program. PIAC also receives funding from the NSW Government Department of Energy and Water for its work on utilities, and from Allens Arthur Robinson for its Indigenous Justice Program. PIAC also generates income from project and case grants, seminars, consultancy fees, donations and recovery of costs in legal actions.

PIAC's work on health consumers' charters of rights

PIAC has undertaken a considerable amount of work in regard to patient, or health consumer charters of rights over its 25-years.

The most considerable piece of work in this area was the development of an Australian Health Consumers' Charter (prepared for the Australian Consumers' Council by PIAC and Ageing Agendas) in 1996. This work consisted of a draft charter for comment as well as a background paper. A copy of this work is attached to this submission (**see Attachment A**).

PIAC thanks the Australian Commission on Safety and Quality in Healthcare (the Commission) for the opportunity to comment on the Draft National Patient Charter of Rights (the Draft Charter). PIAC acknowledges the effort that the Commission has taken to inform relevant organisations that the Draft Charter is available for comment, and for being open to that comment. PIAC believes that the strength of the Charter will be in the willingness of consumer and other relevant organisations to champion its content, and to believe that the Charter has relevance and meaning to consumers. PIAC looks forward to the opportunity to work with the Commission further to progress adoption of the Charter.

PIAC's position on health consumer charters

One of the themes of PIAC's work on charters of health consumer rights has been that the recognition of health consumer rights is not only important for philosophical reasons, or because such rights serve the

interests and safety of consumers, but also because striving to achieve the standards of care articulated in health consumer charters promotes good health management practice.

PIAC is of the view that charters of health consumer rights can serve a number of important purposes. Charters can articulate the community's aspirations for the health care system, they can educate health consumers about what their reasonable expectations of the health care system should or could be, they can assist consumers to voice their concerns when they believe rights have been breached.¹ Importantly, Charters should also assist consumers who are seeking remedies when standards of care have not been met; the assessment as to whether the standard has or has not been reached should be based upon an objective test.

Many individual consumers within the health care system will feel relatively intimidated about the process for complaint, and uncertain about what can be the subject of a complaint. For most people, their experience of health care, in the context of a large institution like a hospital, will involve being more or less incapacitated, the stay being short, and feelings of vulnerability.² In this context, PIAC believes that the articulation of appropriate standards is relevant and important. The development of a national charter could assist in achieving the articulation of those standards. However, standards should not be so general that they are ultimately meaningless.

PIAC attended a Round Table Workshop on the on the Draft Charter on 27 February 2008 in Sydney. At that meeting there was some discussion as to what the name of the final charter should be. Some participants at the Round Table expressed the view that the charter should not include the word 'patient' in its title. This issue goes to the heart of the purpose of the charter. PIAC strongly supports of the use of the word 'patient', as patient rights should be the focus of the document (and, indeed, the rights of patients are the focus of the current draft). However, PIAC would also support as an alternative the use of the term 'health consumer'. PIAC would not, however, support any shift in the focus away from patients or consumers in the title or the content of the draft. PIAC believes that the power imbalance for consumers within the health care system should be openly acknowledged, and that any charter of rights within a health care context ought to be patient, or consumer, focussed.

Rights of health consumers

A Charter of Rights for Health Consumers is ... a means of articulating the expectations of health consumers and a vehicle for ensuring that standards are consumer focussed.³

Rights of health consumers are generally protected in a piece-meal fashion by the law in Australia. Serious cases of medical malpractice will generally result in legal action, with the amount of compensation payable being highly variable. The common law protects a range of rights relating to health care in Australia, for example, the importance of informed consent in regard to medical treatment.⁴ Rights within health care are generally recognised or defended through an individual's ability to establish that a standard of care and a duty to meet that standard of care exists in the relevant circumstances, that the duty of care has been breached, and that the breach resulted in damage or harm to the individual.

The use of litigation is a notoriously difficult way to progress recognition of duties and protection of standards and rights, with the individual litigant facing significant financial risks and personal and emotional

¹ Michael Hogan & Clare Petre, *Documenting the rights of patients at public hospitals - a charter of rights* (1993) 2.

² *Ibid* 2-3.

³ *Ibid* 3.

⁴ *Rogers v Whittaker* [1992] 172 CLR 479.

demands in bringing a test case to extend the scope of the protection. As a result of these difficulties many situations that could usefully test the appropriate standards of health care are never brought to court for decision or are resolved before the court makes its determination. Even where cases are brought to court and are finally determined by the court, the resulting protection is necessarily piece-meal because a case establishes the standard of care specifically in respect of the situation that gave rise to the claim. In some circumstances the health care system responds in a more comprehensive manner, for example, the recognition of the requirements of informed consent to treatment in *Rogers v Whittaker*⁵ has had much broader application than the limited circumstances of that case. However, this is not always the case and more systematic mechanisms for establishing standards of care and rights are needed.

As a result of these difficulties, there is a clear need to be proactive and take a systemic approach to the establishment of standards of care and rights in the health care context. This is a strong argument for charters of health consumer rights to ensure an ongoing standard of quality care in the Australian health care system. Recent public concern about health care in New South Wales, resulting in a Special Commission of Inquiry being established to address these apparent systemic issues is an example of the recognition that parts of our health care systems are potentially in crisis, in terms of the consistent delivery of quality health care and consumer confidence. However, the answer should not be to focus on penalties, compensation or special commissions of inquiry. Incidents that lead to poor outcomes in health care should be avoided in the first instance to the extent possible. Charters of health consumer rights, especially those that are enforceable, could substantially improve the quality of care received by patients over time.

Health as a human right

The rights of citizens in relation to the receipt of health care have been the focus of attention for many years, particularly at the international level. By way of a notable example, the right to health, as enshrined in international law, is not the right to be healthy. The right to health has two basic components: a right to health care and a right to healthy conditions.

The *International Covenant on Economic, Social and Cultural Rights*⁶ (ICESCR), to which Australia is a party, was the first human rights treaty to require State Parties to recognise and realise progressively the right to health, and it provides key provisions for the protection of the right to health in international law. ICESCR expressly states in Article 12 that:

The state parties to the present Covenant recognise the right of everyone to the enjoyment of the highest possible standard of physical and mental health.

The basic consequences of a human rights approach to health are as follows:

- Increased accountability of governments for health.
- Increased attention to the health needs of the poor and otherwise vulnerable and disadvantaged groups, and to the correction of unacceptable imbalances between the health status of different population groups. (State Parties are required to prevent, avoid and halt discrimination.)
- More participatory approaches to the provision of health services and the determinants of health.

⁵ [1992] 172 CLR 479.

⁶ GA Res 2200A (XXI). UN Doc A/6316 (1966), 993 UNTS 3, reprinted in 6 ILM 360 360 (1967), adopted 16 December 1966, entered into force 3 January 1976.

- Governments cease imposing retrogressive measures (take-backs) in health-related legislation and budgetary and administrative practices.
- Governments honour concrete obligations to provide immediately for the minimum standards that are essential to enjoyment of the right to health.
- Governments accept that they have obligations to take progressive steps towards realising fully the right to health and must immediately take steps to set the stage for progress. This includes the setting of goals and targets that will demonstrate progress.⁷

PIAC is of the view that an enforceable national charter of patient rights would also improve the standing and recognition of consumers within the health care sector considerably. As outlined above, PIAC is of the view that this would only serve to improve the delivery of health care in this country.

Patient safety

Patient safety is actually the minimum requirement that the health care sector has to meet, and the hub around which quality systems must be based. Many adverse events can be prevented, some by avoiding medical errors. The health care sector needs to be organised in such a way that professionals are aided in making fewer errors. In order to be more than a potential victim, the patient must be given tools so that he [*sic*] can provide an active contribution to patient-safe health care. However, patient safety is in the first place the responsibility of the care provider.⁸

As with health more generally, the importance of patient safety has been recognised as an issue of international significance. The World Alliance for Patient Safety, in 2005, published the *WHO Draft Guidelines for Adverse Event Reporting and Learning Systems*. This document states:

The most important knowledge in the field of patient safety is how to prevent harm to patients during treatment and care. The fundamental role of patient safety reporting systems is to enhance patient safety by learning from failures of the health care system. We know that most problems are not just a series of random, unconnected, one-off events. We know that health care errors are provoked by weak systems and often have common root causes which can be generalised and corrected. Although each event is unique, there are likely to be similarities and patterns in sources of risk which may otherwise go unnoticed if incidents are not reported and analysed.⁹

PIAC believes that the Draft Charter could be substantially strengthened in regard to outlining the importance of redress when health care systems go wrong. The recognition of errors, and the belief that something will be done about them at a systemic level to prevent those errors happening again, could do much to improve consumer confidence in the health care system, particularly in regard to the health treatment received in hospitals.

PIAC is of the view that the Draft Charter should contain more detail about how services within the health care system could address issues when consumers indicate that a problem has arisen. This is an opportunity to set a new standard in Australia for the management of complaints within a health care setting. PIAC believes that this could do much for improving patient safety in Australia.

⁷ Judith Asher, *The Right to Health: A Resource Manual for NGOs* (2004) 24.

⁸ J K M Gevers, E H Hondius and J H Hubben, *Health Law, Human Rights and the Biomedicine Convention* (2005) 82.

⁹ World Alliance for Patient Safety, *WHO Draft Guidelines for Adverse Event Reporting and Learning Systems* (2005) 6.

Research undertaken in the United States of America, Canada, New Zealand, France, England, Denmark and Australia demonstrates that a large number of patients are affected by adverse events when they seek treatment in a hospital.

Toward the end of 1999 in the United States of America, the Institute of Medicine published a report entitled *To err is human: Building a safer health system*. The report estimated that as a result of preventable 'medical errors', between 44,000 and 98,000 die in hospitals in the USA, a larger number than die in car accidents or through breast cancer or AIDS.¹⁰ Clearly change is needed in regard to minimising the number of adverse events, and Australia is not immune to this need for change.

PIAC believes that a stronger rights-based system for health consumers would go some of the way to providing the impetus to address, at a systemic level, the need to improve health care systems to minimise the incidence of medical errors.

Other jurisdictions

Other jurisdictions, particularly in Europe, are much further advanced than Australia in the recognition of the importance of patient safety and in the protection of the rights of health consumers. Some jurisdictions have recognised the importance of patient rights, and that protecting the rights of health consumers can serve the overall quality of health care delivered not only by individual service providers, but of the system in its entirety.

In Poland, for example, listening to the needs of patients in the health care system is gaining increased attention. In January 2002, the Minister of Health established the Bureau for the Rights of Patients. The Bureau for the Rights of Patients monitors malpractice complaints, access to medical documentation, and the procedures relating to waiting lists, amongst other things. The terms of reference for the Bureau for the Rights of Patients are based on a *Charter of Patient Rights*, which was published by the Minister of Health in 1997. As a result there is a growing expectation of complaints processes, and commentators suggest that this is linked to the ongoing transformation of the entire health care system.¹¹

General comment on draft national patient charter of rights

PIAC is of the view that the Draft Charter contains some important core principles, but that it needs to be strengthened in terms of substance and enforceability. For example, the Draft Charter should set out stronger principles in regard to the provision of redress, remedies or compensation; otherwise the document runs the risk of being tokenistic, and ultimately meaningless to consumers. This will be a missed opportunity to improve standards of care, as well as the rights and safety of patients.

¹⁰ Institute of Medicine, *To err is human: Building a safer health system* (1999) 26, cited in World Alliance for Patient Safety, above n9, 82.

¹¹ J K M Gevers, E H Hondius and J H Hubben, *Health Law, Human Rights and the Biomedicine Convention* (2005) 266-67.

Specific comment on Draft National Patient Charter of Rights

National Patient Charter of Rights and National Patient Charter Principles

It is not clear to PIAC why the National Patient Charter of Rights has been articulated separately to the National Patient Charter Principles. PIAC believes that the Charter Principles are just as relevant in terms of articulating what the rights contained in the Charter actually mean, as the Charter itself. Indeed, as a stand-alone document, the Charter could be viewed as having limited utility, as there is no clear articulation of what the rights contained in it might actually mean. PIAC strongly urges that the final National Patient Charter of Rights and the National Patient Charter Principles be contained in a single document. While the language of the two documents is appropriate, patients should not have to reference a second document in order to access the information currently outlined in the draft National Patient Charter Principles. PIAC has consistently put forward the view that '[a] charter must be comprehensive to fulfil its educative and informative role'.¹² This is best achieved through a single document setting out both the rights, and the principles underpinning and providing interpretation of those rights.

Rights included in the Charter

PIAC has consistently argued that there are some key rights that should form part of a health consumers charter.¹³ Most of those rights have been included in the Draft Charter, however, there is a need to include two additional rights and for a more expansive explanation of some of the rights already included (see the section, 'Points included in the Principles' below). At present, PIAC believes the Draft Charter does not provide sufficient clarity and detail for it to fulfil its roles effectively.

Additional rights that should be included in the Charter

PIAC is of the view that there are two key rights that should be added to the Draft Charter. These rights are:

- the right to access medical/health records; and
- the right to compensation.

The right to access records

PIAC has advocated for a long time that patients should be able to access their health records. This right should be enshrined in the Charter. This right should include that patients have access to all recorded information relating their health care and condition, either personally, or through another person that the patient nominates. Further, patients should be provided with clear and accessible explanation of the contents and of the meaning of any information recorded about their health status or treatment.

PIAC also submits that important elements of this first additional right is that patients should have the right to participate in the recording and keeping of information about their health care and health status and the right to seek an amendment or additions to the information contained in their medical record about their care and condition, and to have their comments attached to any records or files.

¹² Michael Hogan & Clare Petre, above n1, 2.

¹³ Ibid 3.

The right to compensation

As outlined above, patients should have the right to compensation or redress for injuries or damage suffered as a result of the delivery of health care. In this regard, the information contained in the Principles is inadequate and the relevant section of the Draft Charter dealing with redress does not deal with the right to compensation. The right to redress section should be one of the cornerstones that underpins the effectiveness and potential of the document to improve the quality of health care received. The right to access the processes for commenting on care received, the right to receive information about how to make a complaint, and the right to have concerns dealt with properly and promptly, are important elements of the right to redress. However, the absence of compensatory rights means that the Draft Charter is insufficient in its articulation and protection of this important right.

The addition of a section that states, 'A patient is entitled to the payment of compensation where injury or damage has been caused', would substantially strengthen the Draft Charter. The right to redress should include not only the right to comment on care received, but also the right to have any harm suffered remedied.

Ideally, the National Patient Charter of Rights would be enshrined in federal legislation and include enforceable rights, or at least a national complaints mechanism, which could be linked to accreditation. A charter can become essentially meaningless to consumers without appropriate complaint or enforcement mechanisms in place.

Charters of consumer rights in the health context in other jurisdictions contain the right to compensation when a person is injured in a health care setting. The *European Charter of Patient Rights* (ECPR), drafted in 2002 by the Active Citizen Network in Italy, outlines 14 rights of citizens in relation to health care. The *European Charter of Patient Rights* is based on the *Charter of Fundamental Rights* of the European Union, in particular Article 35 on the Right to Health Care. The *European Charter of Patient Rights* aims at raising awareness on patient's rights, concretely improving the respect of patient's rights within all EU countries and empowering consumer organisations in regard to the implementation of patient's rights in Europe. According to the European Economic and Social Committee, while developed by a civil society organisation, the ECPR has:

... now achieved recognition at the level of European institutions and among citizens' organizations involved in health and health care issues.¹⁴

The *European Charter of Patient Rights* recognises both the right to complain, and the right to compensation, as follows:

13 – Right to Complain

Each individual has the right to complain whenever he or she has suffered a harm and the right to receive a response and other feedback.

The health services ought to guarantee the exercise of this right, providing (with the help of third parties) patients with information about their rights, enabling them to recognise violations and to formalise their complaint.

¹⁴ European Economic and Social Committee, 'EESC prize for organised civil society: the European Economic and Social Committee announces the winners for 2007', (2007) <http://www.eesc.europa.eu/sco/prize_civ_soc/index_en.asp> at 7 March 2008.

A complaint must be followed up by an exhaustive written response by the health service authorities within a fixed period of time.

The complaints must be made through standard procedures and facilitated by independent bodies and/or citizens organizations and cannot prejudice the patient's right to take legal action or pursue alternative dispute resolution.

14 – Right to Compensation

Each individual has the right to receive sufficient compensation within a reasonably short time whenever he or she has suffered physical or moral and psychological harm caused by health service treatment.

The health services must guarantee compensation, whatever the gravity of the harm and its cause (from an excessive wait to a case of malpractice), even when the ultimate responsibility cannot be absolutely determined.¹⁵

There are, in PIAC's view, two ways to include the right to compensation. The first option is to retain and expand the right to redress, as compensation is a form of redress. The second is to adopt the approach in the ECPR and rename the right to redress, 'the right to complain', and to add a newly articulated right: the right to compensation.

If the first option is chosen, the Draft Charter and Principles require amendment to ensure that the right to redress includes the right to having harms or injuries remedied through compensation and other forms of redress, and that the existing material on the right to complain be supplemented to ensure it is clear that this right include assistance to participate in the complaint process, to have access to an independent process.

If the second option is chosen, the current right to redress should be renamed the right to complain and needs to be supplemented with the material in respect of the right to complain set out in the previous paragraph, and a new right added, the right to compensation' that sets out the scope of compensation and other forms of redress separately.

Points included in the Principles

While the current draft provides an effective articulation of many key elements of the rights set out in the Draft Charter, there are several gaps that could usefully be filled to ensure the resulting document provides helpful guidance not only to health consumers but also to health service providers.

The following would provide a useful addition to the Principles:

Access: Equity of access to public health care

The current principles quite properly identify the need to ensure equity of access irrespective of place of residence, and that capacity to pay should not be a barrier to accessing effective health care. These are not, however, the only equity issues that arises in the provision of health care. The right to equitable access should be extended to include access irrespective of gender, race, culture, ethnicity, sexuality, health status, disability (including intellectual and psychiatric disabilities), age, beliefs, or legal status.

This would complement the principles set out under 'Respect: Respect, dignity and consideration'.

¹⁵ Active Citizenship Network, *European Charter of Patient Rights* (2002) 9.

Respect: Respect, dignity and consideration

The list of personal characteristics could usefully be expanded to provide better guidance to health care providers. The list set out in the previous section is a more expansive articulation of the personal characteristics that should be respected in the delivery of care.

Communication: communicating clearly throughout the period of care

This principle could usefully be supplemented with a clear statement of the entitlement to be provided with information in a form and format that is accessible to the person. While Australia is yet to ratify the UN *Convention on the Rights of Persons with Disabilities*¹⁶, it has signed it and indicated its intention to progress towards ratification. The Convention includes in Article 21 the right to information in formats that are accessible to people with a disability.

Information: being informed about services, treatment and care

Again, the principles set out under this heading are appropriate. There is only one additional entitlement that PIAC urges be included: the right to ask questions and be provided with clear, comprehensible and comprehensive answers.

Participation: informed decision making and informed choices

Consistent with Article 12 of the UN *Convention on the Rights of Persons with Disabilities*, this should include the principle that capacity be presumed. It is important that a person's capacity to participate in informed decision making and informed choices be supported and respected. This section should also recognise the developing capacity of children, consistent with Articles 5 and 12 of the UN *Convention on the Rights of the Child*¹⁷, and that their capacity to be involved should be respected and encouraged.

Further, the right to choose to participate in teaching, training and research should be clearly drafted to ensure that it is understood to include the right to choose **not** to participate.

Privacy: ensuring personal information is secure

The right to privacy articulated in the draft is very narrow. The heading and content should be amended to include the right to privacy in treatment, that is, the right to receive care in privacy.

Location of the principles

PIAC is of the view that the explanations included in the Principles assist in the understanding of the rights and responsibilities of patients and providers. However, PIAC believes that the principles and the charter document should be combined to create a single document so that the charter has greater depth, and relevance to consumers. This is consistent with the need to ensure the charter achieves its potential as an educative document.

Rights and responsibilities

PIAC believes that there is an appropriate balance between the rights, roles and responsibilities in the Principles. PIAC does not believe that there should be a stronger emphasis on patient responsibilities.

¹⁶ GA Res 61/106 UN Doc A/Res/61/106 (2006), adopted 13 December 2006, yet to enter into force. Australia signed the Convention on 31 March 2007, the day it was opened for signature.

¹⁷ GA Res 44/25 UN Doc A/Res/44/25 (1989), adopted 13 December 2006, entered into force 2 September 1990. Australia ratified the Convention on 16 January 1991.

Conclusion

PIAC has welcomed the opportunity to comment on the Draft National Patient Charter of Rights and the National Patient Charter Principles. PIAC has advocated for the need for a national charter of health rights for many years. However, whilst the Draft Charter and the Principles contain some important aspirational concepts, the documents should go much further in terms of ensuring that the principles that underpin the Charter are applied consistently in the delivery of health care throughout Australia. PIAC believes that the Draft Charter would be strengthened by the inclusion of the right to compensation when injury can be established, as well as other important enforcement mechanisms.

Attachment A

Australian Charter of Rights of Health Consumers

Developed by the Public Interest Advocacy Centre, July 1994

Australian Charter of Rights of Health Consumers

prepared by the Public Interest Advocacy Centre
for the Australian Consumers Council
workshop 28-29 July 1994

Principles

The Charter of Rights for health consumers is based on the following fundamental principles¹:

- A. People are entitled to a healthy and safe environment in which to live and work. That is:
 - basic needs are met
 - the physical environment enhances quality of life
 - there is protection from health hazards.
- B. People are entitled to adequate, accurate information and education enabling them to make informed decisions which promote health and prevent ill health and disability.
- C. People are entitled to participate in the development, monitoring and implementation of social and economic policies and programs.
- D. People are entitled to equal access to health services which:
 - promote health
 - prevent and alleviate ill health and disability
 - provide health care.
- E. People are entitled to determine whether or not to seek assistance from health workers.
- F. These Principles are in keeping with Covenants of the United Nations, in particular,
 - The International Covenant on Civil and Political Rights
 - The International Covenant on Social, Economic and Cultural Rights
 - The Declaration of the Rights of the Child
 - The Declaration of the Rights of Mentally Retarded Persons
 - UN Convention of the Rights of the Child.
- G. These principles are consistent with the provision of universal access to health care through Medicare.

1. Consumers' Health Forum of Australia, *Legal Recognition and Protection of the Rights of Health Consumers*, November 1990, page 103.

Rights

1. Access to health care

- 1.1 You have the right to appropriate, safe and prompt health care when you need it. This includes the right to receive:
- preventative care and health promotion services; and
 - acute care and emergency medical care at hospital casualty or accident and emergency departments.
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- 1.2 You have the right to quality health care when you need it. This means care that is competent and of a reasonable standard.
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- 1.3 You have the right to health care on the basis of medical need rather than ability to pay or insurance status.
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- 1.4 You have the right to choose whether to be treated as a public or private patient in a public hospital, and the right to know what this decision means.
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- 1.5 You have the right to health care regardless of social or financial status, age, sex, race, religion, political belief, sexuality, disability, health or legal status.
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- 1.6 You have the right to have continuity of care, including planning of your continuing health or social care before you are discharged from hospital, and follow up after you are discharged. This planning may need to start even before you are admitted.
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2. Information

- 2.1 You have the right to have all information about your health condition, prognosis and treatment given to you in clear, understandable language.
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2.2 You have the right to the information necessary for you to make informed decisions about your health care, including:

- details of all proposed procedures and therapies, as well as possible alternatives, including
 - whether the procedure is experimental or to be used in research
 - expected outcomes
 - side-effects and after-effects
 - chances of success
 - material risks and risks of concern to you.
 - likely further treatment
 - time involved in treatment and recovery, and
 - convalescence and rehabilitation requirements;
- results of any procedures which have been carried out and the implications of those results;
- whether your condition is curable;
- possible consequences of not taking the advice of the health worker.

2.3 You have the right to be introduced to the person primarily responsible, as well as the other people involved in, your care, and to be informed of their name, qualifications and experience.

2.4 You have the right to ask questions, and to be given complete, direct and honest answers, about your medical condition, prognosis and treatment.

2.5 You have the right to have a qualified health interpreter present when requested.

2.6 You have the right to information about the health care system, including local services and facilities, and quality standards.

2.7 You have the right to know about any waiting lists for treatment for your condition, your place in any waiting list and expected waiting times.

2.8 You have the right to advice about:

- self care, drug administration, special precautions which may be necessary or desirable;
 - any special associations, facilities, aids or appliances which may help you.
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3. Informed decisions

3.1 You have the right to determine what happens to you, to participate fully in decision-making and to take an active role in your health care, including:

- to give your explicit consent before any procedure can be carried out (except for emergencies);
- to receive sufficient explanation of any document you are asked to sign before treatment or at any other time;
- to decide on admission to and discharge from hospital; and
- to participate in medical research or undergraduate professional teaching.

3.2 You have the right to authorise another person to make decisions for you in the event that you are unable to do so.

3.3 Subject to the court's power to decide otherwise, if you are a parent or guardian, you have the same rights on behalf of your child or ward.

3.4 As they get older, children acquire an increasing capacity to make decisions on their own behalf, and have the right to be consulted.

4. Refusal of treatment

4.1 You have the right to refuse treatment, including:

- to choose to leave your condition untreated
- to refuse admission to a health care facility regardless of your condition or against medical advice
- to withdraw your consent to a procedure
- to refuse to allow a procedure to be carried out
- to refuse health care from a particular health worker
- to refuse to participate in research and experiments
- to leave a hospital or other health service at any time
- to refuse life prolonging treatment or to receive only palliative care.

4.2 You have the right to change your decision at any time.

5. Second opinions, support & advocacy

5.1 You have the right to seek information and advice from other sources.

5.2 You have the right to seek a second opinion about any health matter.

5.3 You have the right to decide who will be present during your health care. You can insist on the presence or not of other people, including health workers not directly involved in your care, students, researchers, and others including family members.

5.4 If your child is in hospital you have the right to stay with the child at all times, except where separation is necessary for medical reasons. Conversely, children have a right to have their parents present.

5.5 If you are terminally ill, you have the right of access to relatives and / or friends on a full time basis if you wish.

5.6 In order to have your needs and interests represented to those providing for the care and treatment of you and other patients, you have the right to consult with, to nominate or to establish groups with other patients, friends, relatives and advocates.

5.7 You have a right to expect that health professionals will advocate on your behalf when asked to do so.

5.8 You have the right to obtain your own legal or other advice if you feel that a complaint you have made has not been adequately dealt with or when you wish to seek redress for injury or damage resulting from your health care.

6. Privacy and Respect

6.1 You have the right to receive health care in privacy.

6.2 You have the right to be treated with dignity and courtesy, and to have due consideration given to your background, needs and wishes.

6.3 You have the right to respect for your ethnic, cultural or religious beliefs and practices, and your conscientious convictions.

6.4 You have the right not to be abused or exploited sexually, physically or emotionally by the provider of a health service.

6.5 You are entitled to die with dignity.

7. Confidentiality

- 7.1 You have the right (apart from limited legal exceptions) to have all identifying personal information kept confidential. No identifying information about you, your condition or treatment should be made available to anyone else without your consent.
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8. Access to medical / health records

- 8.1 You have the right to participate in the recording and keeping of information about your health status and care, including:
- to have access to all recorded information relating to your health care and condition, either personally or through another person you nominate;
 - to be given an explanation of the contents and meaning of any recorded information; and
 - to seek amendment or additions to all information relating to your health care and condition, and to have your comments attached to any records or files
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9. Costs

- 9.1 You have the right to be treated free of charge as a public patient in a public hospital.
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- 9.2 You have the right to know about the expected costs of any proposed treatment, tests or other health-related service for which fees are charged.
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- 9.3 You have a right to an itemised account and to query any item.
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- 9.4 You have the right to pay no more than the agreed fee, or in the absence of an agreement then a reasonable fee, for any treatment, tests or other health-related service.
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10. Complaints

- 10.1 You have the right to comment on, and / or complain about your health care, and to have your complaint dealt with properly and promptly.
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- 10.2 You have the right to be told about and given access to the procedure for complaining within the health care service of your provider, and to an independent health complaints authority.
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11. Compensation

11.1 You have the right to redress for injuries or damage suffered as a result of your health care.

12. Health Policy

12.1 You have the right to be involved in representation of the interests of citizens, consumers and communities in:

- the development of health care policy priorities and planning,
- the running of local health care services and
- in quality assurance and evaluation programs.

RIGHT	BASIS	ENFORCEMENT
<p>1. Access to health care</p>		
<p>1.1 You have the right to appropriate, safe and prompt health care when you need it. This includes the right to receive:</p> <ul style="list-style-type: none"> • preventative care and health promotion services; and • acute care and emergency medical care at hospital casualty or accident and emergency departments. 	Medicare.	Civil action for damages, Complaints / disciplinary action.
<p>1.2 You have the right to quality health care when you need it. This means care that is competent and of a reasonable standard.</p>	Medicare. Common law.	Civil action. Complaints / disciplinary action.
<p>1.3 You have the right to health care on the basis of medical need rather than ability to pay or insurance status.</p>	Medicare (exception for non residents).	Civil action. Complaints / disciplinary action.
<p>1.4 You have the right to choose whether to be treated as a public or private patient in a public hospital, and the right to know what this decision means.</p>	Medicare.	Not enforceable.
<p>1.5 You have the right to health care regardless of social or financial status, age, sex, race, religion, political belief, sexuality, disability, health or legal status.</p>	Discrimination legislation - federal and some states. (Partial and varying right depending on where you live).	Complaint of discrimination. Complaints / disciplinary action.
<p>1.6 You have the right to have continuity of care, including planning of your continuing health or social care before you are discharged from hospital, and follow up after you are discharged. This planning may need to start even before you are admitted.</p>	Some charters.	Complaints / disciplinary action.

RIGHT	BASIS	ENFORCEMENT
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2. Information

<p>2.1 You have the right to have all information about your health condition, prognosis and treatment given to you in clear, understandable language.</p>	<p>Medicare, Common law (partial)</p>	<p>Civil action, Complaints / disciplinary action.</p>
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<p>2.2 You have the right to the information necessary for you to make informed decisions about your health care, including:</p>	<p>Civil action, Complaints / disciplinary action.</p>
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- details of all proposed procedures and therapies, as well as possible alternatives, including
 - whether the procedure is experimental or to be used in research
 - expected outcomes
 - side-effects and after-effects
 - chances of success
 - material risks and risks of concern to you.
 - likely further treatment
 - time involved in treatment and recovery, and
 - convalescence and rehabilitation requirements;
- results of any procedures which have been carried out and the implications of those results;
- whether your condition is curable; and
- possible consequences of not taking the advice of the health worker.

<p>2.3 You have the right to be introduced to the person primarily responsible, as well as the other people involved in, your care, and to be informed of their name, qualifications and experience.</p>	<p>Some charters.</p>	<p>Complaints / disciplinary action.</p>
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RIGHT	BASIS	ENFORCEMENT
2.4 You have the right to ask questions, and to be given complete, direct and honest answers, about your medical condition, prognosis and treatment.	Common law.	Civil action. Complaints / disciplinary action.
2.5 You have the right to have a qualified health interpreter present when requested.	Possible common law. Charters	Needs to be tested in civil action.
2.6 You have the right to information about the health care system, including local services and facilities, and quality standards.	Some Charters	Not enforceable.
2.7 You have the right to know about any waiting lists for treatment for your condition, your place in any waiting list and expected waiting times.	Medicare	Complaints / disciplinary action.
2.8 You have the right to advice about: <ul style="list-style-type: none"> • self care, drug administration, special precautions which may be necessary or desirable; • any special associations, facilities, aids or appliances which may help you. 	Moral right / expectation only.	Not enforceable.

RIGHT**BASIS****ENFORCEMENT****3. Informed decisions**

<p>3.1 You have the right to determine what happens to you, to participate fully in decision-making and to take an active role in your health care, including:</p> <ul style="list-style-type: none"> • to give your explicit consent before any procedure can be carried out (except for emergencies); • to receive sufficient explanation of any document you are asked to sign before treatment or at any other time; • to decide on admission to and discharge from hospital; and • to participate in medical research or undergraduate professional teaching. 	<p>Civil law [<i>Rogers v Whitaker</i>], Medicare / Charters. Criminal law: trespass/assault. (There are some exceptions such as mental health law or laws relating to communicable diseases.)</p>	<p>Civil action. Complaints / disciplinary action. Criminal action.</p>
<p>3.2 You have the right to authorise another person to make decisions for you in the event that you are unable to do so.</p>	<p>Statutory provision for 'living wills' / powers of attorney in some states / territories only.</p>	<p>Possible equity action.</p>
<p>3.3 Subject to the court's power to decide otherwise, if you are a parent or guardian, you have the same rights on behalf of your child or ward.</p>	<p>Common law. With <i>Family Law Act</i>. State child welfare and minors legislation.</p>	<p>Civil action. Orders under Family Law Act / state legislation. Complaints / disciplinary action.</p>
<p>3.4 As they get older, children acquire an increasing capacity to make decisions on their own behalf, and have the right to be consulted.</p>	<p>Common law. [<i>Re Gillick</i> (UK)]</p>	<p>Complaints / disciplinary action.</p>

RIGHT	BASIS	ENFORCEMENT
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4. Refusal of treatment

<p>4.1 You have the right to refuse treatment, including:</p> <ul style="list-style-type: none"> - to choose to leave your condition untreated - to refuse admission to a health care facility regardless of your condition or against medical advice - to withdraw your consent to a procedure - to refuse to allow a procedure to be carried out - to refuse health care from a particular health worker - to refuse to participate in research and experiments - to leave a hospital or other health service at any time - to refuse life prolonging treatment or to receive only palliative care. 	<p>Common law, Criminal law.</p>	<p>Civil action, Criminal actions for false imprisonment, assault, trespass, Complaints / disciplinary action.</p>
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<p>4.2 You have the right to change your decision at any time.</p>	<p>Common law (implicit in concept of informed consent).</p>	<p>Rights generally untested</p>
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5. Second opinions, support & advocacy

<p>5.1 You have the right to seek information and advice from other sources.</p>	<p>Charters Moral right</p>	<p>Doubtful enforcement</p>
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<p>5.2 You have the right to seek a second opinion about any health matter.</p>	<p>Medicare / Charters.</p>	<p>Doubtful enforcement</p>
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<p>5.3 You have the right to decide who will be present during your health care. You can insist on the presence or not of other people, including health workers not directly involved in your care, students, researchers, and others including family members.</p>	<p>Some charters</p>	<p>Doubtful enforcement Complaints / disciplinary action.</p>
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RIGHT	BASIS	ENFORCEMENT
5.4 If your child is in hospital you have the right to stay with the child at all times, except where separation is necessary for medical reasons. Conversely, children have a right to have their parents present.	Some charters	Not generally tested
5.5 If you are terminally ill, you have the right of access to relatives and / or friends on a full time basis if you wish.	Moral right / expectation only.	Doubtful enforcement
5.6 In order to have your needs and interests represented to those providing for the care and treatment of you and other patients, you have the right to consult with, to nominate or to establish groups with other patients, friends, relatives and advocates.	Some charters. Moral right / expectation only.	Doubtful enforcement
5.7 You have a right to expect that health professionals will advocate on your behalf when asked to do so.	Moral right / expectation only.	No enforcement.
5.8 You have the right to obtain your own legal or other advice if you feel that a complaint you have made has not been adequately dealt with or when you wish to seek redress for injury or damage resulting from your health care.	Civil right.	Civil right.
6. Privacy and Respect		
6.1 You have the right to receive health care in privacy.	Medicare. Charters. Cwith Privacy legislation.	Complaints / disciplinary action. Complaint under Privacy legislation.

RIGHT	BASIS	ENFORCEMENT
6.2 You have the right to be treated with dignity and courtesy, and to have due consideration given to your background, needs and wishes.	Charters	Complaint / disciplinary action.
6.3 You have the right to respect for your ethnic, cultural or religious beliefs and practices, and your conscientious convictions.	Discrimination legislation in some jurisdictions (partial). Otherwise, moral right / expectation only. (Some exceptions implied by criminal law).	Complaint / disciplinary action.
6.4 You have the right not to be abused or exploited sexually, physically or emotionally by the provider of a health service.	Common law. Criminal law.	Civil action. Criminal prosecutions. Complaint / disciplinary action.
6.5 You are entitled to die with dignity.	Moral right / expectation.	Doubtful enforcement.
7. Confidentiality		
7.1 You have the right (apart from limited legal exceptions) to have all identifying personal information kept confidential. No identifying information about you, your condition or treatment should be made available to anyone else without your consent.	Probable common law. Cwith <i>Privacy Act</i> (limited). Some exceptions in legislation / legal process.	Possible civil action. Complaint under Cwith <i>Privacy Act</i> . Possible breach of contract.

RIGHT	BASIS	ENFORCEMENT
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8. Access to medical / health records

<p>8.1 You have the right to participate in the recording and keeping of information about your health status and care, including:</p> <ul style="list-style-type: none"> • to have access to all recorded information relating to your health care and condition, either personally or through another person you nominate; • to be given an explanation of the contents and meaning of any recorded information; and • to seek amendment or additions to all information relating to your health care and condition, and to have your comments attached to any records or files 	<p>Possible common law right of access. FOI Act in most states / territories. (Partial: applies only to public health system, subject to therapeutic privilege). Moral right / expectation only.</p>	<p>Possible equity action. FOI applications re public services. Private and public information by subpoena in court proceedings. FOI application to amend.</p>
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9. Costs

<p>9.1 You have the right to be treated free of charge as a public patient in a public hospital.</p>	<p>Medicare / Charters.</p>	<p>Enforceable</p>
<p>9.2 You have the right to know about the expected costs of any proposed treatment, tests or other health-related service for which fees are charged.</p>	<p>Consumer protection legislation.</p>	<p>Consumer protection action.</p>
<p>9.3 You have a right to an itemised account and to query any item.</p>	<p>Consumer protection legislation.</p>	<p>Consumer protection action.</p>
<p>9.4 You have the right to pay no more than the agreed fee, or in the absence of an agreement then a reasonable fee, for any treatment, tests or other health-related service.</p>	<p>Consumer protection legislation.</p>	<p>Consumer protection action.</p>

RIGHT	BASIS	ENFORCEMENT
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10. Complaints

10.1 You have the right to comment on, and / or complain about your health care, and to have your complaint dealt with properly and promptly.

Medicare / Charters.
Legislation in some states / territories.

Enforceable only where statutory basis.

10.2 You have the right to be told about and given access to the procedure for complaining within the health care service of your provider, and to an independent health complaints authority.

Medicare / Charters

Doubtful enforcement.

11. Compensation

11.1 You have the right to redress for injuries or damage suffered as a result of your health care.

Common law (partial - not for misadventure)

Civil action where negligence.

12. Health Policy

12.1 You have the right to be involved in representation of the interests of citizens, consumers and communities in:

- the development of health care policy priorities and planning,
- the running of local health care services and
- in quality assurance and evaluation programs.

Civil / consumer expectation.
Some statutory bases for participation in boards etc. (Indirect base in environmental planning legislation.)

No enforcement.