



HEALTH RIGHTS & COMMUNITY ACTION Inc

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Friday, March 14, 2008

Dr Nicola Dunbar
GPO Box 5480
Sydney
NSW 2001

Dear Dr Dunbar

We are pleased that the Safety & Quality Commission on Health Care has given priority to the Patients Rights Charter in its work. We feel it is extremely important that a National Patients Charter becomes the foundation for all Rights Charters throughout Australia.

Currently there is a plethora of "charters" throughout Australia, with many having different key points and principles underpinning them. As both consumers and providers travel across borders, as well as between the public and private system, sometimes within the same episode of care, the current situation makes it extremely difficult for all to know where they stand.

We are very supportive of the format, with the points succinctly spelt out. The supporting principles are also clear and give a good explanation. We have a few suggested changes including:

- Right to change mind
- Second opinion
- Access to medical records and have amended
- Complain
- Compensation

These are spelt out in detail in the attached document.

The Charter will provide a necessary framework to ensure all States and Territories have concisely written documents which assist users of health services to access their rights. The guiding principles of all Charters should be that they have the same key principles, follow similar formatting and are written to a reading age of 12 years literacy level.

In South Australia the current Charter "Your Rights and Responsibilities – A Charter for South Australian Public Health System Consumers" is one of numerous charters, with many hospitals developing their own, as well as sections within these hospitals developing still more. Then there is the Private Patients Charter, individual private hospital charters, other health service charters, and so the list goes on, making it extremely difficult for consumers to know their rights. Adding to this the Health & Community Services Complaints Commissioner who is in the process of developing the Commissioner's own charter. We feel it makes sense to minimize the creation of too many charters.

One of the major problems SA has with its State Charter is that the individual services pay for each charter, hence many services are reluctant to have or display it. We have seen SA Charter Booklets in waiting areas within outpatient departments of hospitals with big stickers on the front saying "Do Not Remove". One of the guiding principles must be that Charters are provided freely to hospitals and can be easily obtained. Services should be encouraged to distribute the Charter.

We are strongly opposed to any inclusion of responsibilities in the Charter. All rights documents are derivatives of the UN Declaration of Human Rights which does not include responsibilities. The Declaration of Human Rights does have two principles which states that when exercising rights, the rights of another individual must not be compromised. We support the inclusion of such a principle in the Charter.

National Patients Charter and Principles

We support the existence of both the Charter and Principle

We feel this format assists both users and providers of health services clearly understand their rights.

The language used in the Charter and Principles is generally good, however we feel the Charter should be more upfront about complaints and forms of redress including the right to compensation.

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he table format on page 5 of the Consultation Paper provides an excellent format for all to clearly understand their rights. The Principles that follow unpack these rights well and will be beneficial to users and providers.

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The table format on page 5 of the Consultation Paper provides an excellent format for all to clearly understand rights. The Principles that follow unpack these rights well and will be beneficial to users and providers.

Rights Included in Charter

We feel a few additions are needed in the Charter to ensure that users rights clear. . These include:

Right to change mind

Second opinion

Access medical records and have amended

Complain

Compensation

These are spelt out in detail in the attached document

Points included in Principles.

We believe the Principles are a good explanation of rights. As mentioned previously we do not support the inclusion of responsibilities in the Charter.

The attached document shows the changes we suggest.

Rights and Responsibilities – covered previously.

In line with the UN Declaration of Human Rights we suggest something similar to, *“The rights contained within this Charter may not be interpreted to take away the rights of another user or provider of health services.”*

Existing Charters

The European Charter of Patients’ Rights is the Charter we feel that is unsurpassed in its scope of rights.

The National Charter will ensure consistency in Charters across Australia. By becoming the template by which all State and Territory charter are developed.

Possible uses of the Charter.

We see linking the Charter to initial training as well as ongoing training of all health professionals and for use in accrediting health services being essential for the success of the Charter.

Linking the Charter to Australian Health Care Agreements as well as all services which attract Commonwealth funds through Medicare.

As all States and Territories all have Complaints Commissioners these Commissioners developing each sectors Charters within their jurisdiction would ensure consistency within each State. Consistency would then occur.

These measures will ensure the Charter is not a “toothless tiger”.

How the Charter applies in different sectors and setting.

The Charter clearly defines rights. The inclusion of Legislative requirements where applicable would further strengthen the Principles document. The development of other resources for providers of services would be beneficial. Careful consideration needs to be given increasing the length of the Charter and Principles as this could lead to the documents marginalizing those without good literacy levels.

We look forward to the final charter and to the implementation and flow through to all States and Territories.

Yours sincerely

Pam Moore
For HR&CA
Cc. Consumers Health Forum.

Health Rights & Community Action's Response to the Draft National Patient Charter of Rights

Table of our submission

Additions to text are bold italicized and size 14 text, Arial font.

Our explanations are size 12 text, Times New Roman font

Introduction

The purpose of the National Patient Charter of Rights is to support safe and high quality care by articulating the key rights of all patients when seeking health care anywhere in Australia. We agree.

Rights included in the Charter

The National Patient Charter of Rights is based on eight key patient rights.

We suggest that the Charter be based on eleven key principles.

These are:

- Access:** Equity of access to public health care (additional) ***including environmental and preventative health care***
- Respect:** Respect, dignity and consideration
- Safety:** Promoting safe and competent (additional) ***quality*** care
- Communication:** Communicating clearly communication throughout the period of care
- Information:** Being informed about services, treatment care (additional) ***and any associated costs***

The financial costs of a procedure are important and need to be spelt out clearly prior to making decisions about future care. We feel it is important to spell this out in the charter brief document. Informed decision making can only occur when important implications including financial one are clearly set out.

- Participation:** Informed decision making and informed choices (additional) ***including changing mind and withdrawing consent.***

People often feel trapped when they have given consent and that they are not entitled to change their mind. We feel it is important to spell this out in the charter brief document.

(additional point) ***A second opinion***

We feel whilst this is covered under participation it is important that this becomes a separate point, as it requires emphasis.

- Privacy:** Ensuring personal information is secure

(additional point) ***Access medical records: entitled to access their own medical records and to have records amended if incorrect***

This right might be implied in privacy but we often hear that people's records are wrong. The most recent case we have heard is the mistake with a person's age. The records stated the person 18 years older than they were, that is it appeared the person was 84 years old. The fatal consequence was the person was only offered palliative treatment for a blocked artery. What was required was a stent, which many 67 year olds receive with good results. We feel it is important to spell this out in the charter document.

(additional point) ***Complain: A person is entitled to complain, through a process which is transparent and follows natural justice principles. This includes being informed of the outcome of the complaint.***

We are of the firm belief that the word “**complaint**” must be used up front in the document. The majority of people by their nature dislike complaining. However complaints are a crucial mechanism that can rectify and improve the system, by feeding users experiences into the safety loop. The inclusion of complaints up front in the Charter will also assist service providers to see complaints as a natural occurrence within health services delivery. This will assist in attitudinal change regarding complaints.

(additional point) **Compensation: in the event of injury**

Users of health services need to be informed that they have a right under common law to compensation for adverse treatment which has resulted in a significant affect on their life. **Consumers’ International web page explanation of consumers “right to redress - to receive a fair settlement of just claims, including compensation for misrepresentation, shoddy goods or unsatisfactory services.** “ This right must be clearly spelt out to health consumers.

Responsibilities. We do not believe responsibilities should be part of a rights based document and draw on the Declaration of Human Rights which is the precursor to all rights based documents. Article 29. of the Declaration of Human Rights states “(1) *Everyone has duties to the community in which alone the free and full development of his personality is possible.*

(2) In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

(3) These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.”

Article 30 states:” *Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.”*

We therefore believe something like the following sentence would be appropriate at the end of the Charter.

The rights contained within this Charter may not be interpreted to take away the rights of another user or provider of health services.

1. ACCESS: Equity of access to public health care

A patient is entitled to:

- care that is appropriate, timely, and based on need, not the ability to pay
- be admitted to a public hospital as a public or a private patient
- equitable access to public health services regardless of place of residence.

We are concerned with this statement as it may create unrealistic expectations for rural consumers

- a decision by a health service regarding access to care that is transparent and accountable

2. RESPECT: Respect, dignity and consideration

There must be mutual respect, dignity and consideration between a patient and a health care provider. This should be at all stages of care and treatment.

A patient is entitled to:

- care provided in a manner that is respectful of a person’s culture, beliefs, values and other personal characteristics such as age and gender
- relief from suffering, including palliative care, that is dignified, comforting and supportive

3. SAFETY: Promoting safe and competent quality care

A patient is entitled to:

- health care services provided with professional care, skill and competence
- care that is informed and clinically appropriate

- care that is provided by the most appropriate health care professional
- effective continuity of care and appropriate referrals
- an environment where systems and staff are working to ensure patient safety

4. COMMUNICATION: communicating clearly throughout the period of care

A patient is entitled to:

- open and appropriate communication throughout the period of care, particularly when plans change or if something goes wrong
- information in a language that can be understood **and where possible be provided with printed fact sheets.**

- access to a qualified health interpreter, **or an interpreter service**

This will ensure that all are aware they have a right to receive some level of interpreting, either personally or through a telephone interpreter service.

- advice on how to ask questions and obtain information about diagnosis, treatment and care from members of the health care team
- users are encouraged to** ask questions and receive a response that addresses their questions in an understandable, adequate and meaningful manner

5. INFORMATION: being informed about services, treatment and care

A patient is entitled to information:

- about their health care
- that explains the difference between accessing public hospital services as a public or a private patient
- on the estimated cost of a health provider's services prior to the delivery of treatment, where relevant and possible
- about estimated waiting times for a health provider's services, and, where known, information about alternative service providers
- that satisfies them about any proposed treatment and medication, including the possible risks and alternatives
- about who is providing care, particularly in a public teaching hospital or health facility where the health care team can vary
- about their care being handed over to the next health care provider, with regard for confidentiality, where possible
- about continuing health care, including medication, care planning, timely and appropriate referrals, convalescence, rehabilitation, and end of life care
- about discharge and continuing health care arrangements when in hospital

Patients (who are able) are expected to provide information about their history, current treatment, medication and alternative therapies directly or through their family, carer or other nominated support person

Patients are expected to follow plans that have been agreed with the health care provider and to report any changes in their condition

6. PARTICIPATION: informed decision making and informed choices

A patient is entitled to:

- be involved in making informed decisions about treatment and care to the degree and extent that they choose
- involve family, carers or other nominated support people in health care treatment, support, decision-making, participation and communication
- give informed consent prior to any procedure, with discussion of options available, expected outcomes for each option, and success rates and incidence of side-effects for each option
- seek a second opinion
- withdraw consent or refuse further treatment, even if previous consent has been given to the treatment or procedure
- choose to participate in teaching, training or research activities, apart from the normal care delivered in a public hospital by clinicians in training
- ask for further information if there is any uncertainty about their care

7. A second opinion

8. PRIVACY: ensuring personal information is secure

A patient is entitled to expect that the collection, use, disclosure and storage of their personal health and other information will be undertaken in accordance with relevant privacy legislation and remain confidential, unless legislation requires disclosure or they direct otherwise

9. Access medical records: *A patient is entitled to see their medical records and have amended if incorrect.*

An explanation is given at the bottom of page one.

10. Complain: *A person is entitled to complain and have complaint addressed*

A patient is entitled to:

- have access to **complain about** the care received
- have their **complaint** dealt with properly and promptly
- Know the outcome and changes that result**
- Without the fear of refusal of treatment or intimidation**

11 Compensation: *seek compensation in the event of injury*

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