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**Joint Submission to ACT Health on  
the Draft**

**Public Patients' Charter**

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**August 2005**

We acknowledge that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders and recognise the displacement and disadvantage they have suffered since European settlement. ACTCOSS celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

## **About HCCA**

The Health Care Consumers' Association (HCCA) of the ACT is the principal health consumer organisation in the ACT. For more than 25 years the Association has been actively involved in promoting consumer participation, and in training and supporting consumers to participate effectively at all levels of health care planning, policy development and service delivery. HCCA also collaborates with government and non government organisations on special projects, and receives funding from Act Health.

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## **About ACTCOSS**

The ACT Council of Social Service Inc. (ACTCOSS) is the peak representative body for not-for-profit community organisations, people living with disadvantage, and low-income citizens of the Territory. ACTCOSS is a member of the nationwide COSS network, made up of each of the state Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS' objectives are representation of people living with disadvantage, the promotion of equitable social policy, and the development of a professional, cohesive and effective community sector.

The membership of the Council includes the majority of community based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

ACTCOSS receives funding from the Community Services Program (CSP) which is funded by the ACT Government.

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## Abbreviations

ACT	Australian Capital Territory
ACTCOSS	ACT Council of Social Service, Inc.
HCCA	Health Care Consumers Association
HACC	Health and Community Care

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## Background

The Health Care Consumers Association of the ACT (HCCA) and the ACT Council of Social Service (ACTCOSS) facilitated a forum to discuss the draft Public Patient's Charter on 15 July 2005. This comment details the outcomes from that discussion.

## Definitions and Scope

In general, discussants did not clearly understand the scope of the draft Charter.

Whilst the preamble indicates a wide application with respect to the definition of health consumer and health service, (that is, to include people with disability and disability services, community sector services and so on), the charter largely relates to hospital services. The draft Charter is in large part, therefore, a *Public Hospital Patients' Charter*. However, the use of the term "public" in this context is also confusing bearing in mind the distinction between a public and private patient. There is a need to clarify the actual scope intended for the Charter.

Discussants were also unsure what remedies would be available to patients when the final Charter was implemented. Would there be an accountability process established should the principles be transgressed?

The Forum discussants also considered that the draft Charter confuses principles with a process for implementation.

- Principles should be separated from process and only the Principles covered in the final Charter.
- A revised Charter should be couched in best-practice terms, and therefore terms like "where possible" and so on should be deleted.

Given these observations, some of the more detailed comments below might more appropriately be included in a "processes document" rather than the final version of the Charter.

These issues of definition and scope affect the entire document and until the scope of the Charter is clarified the discussants noted that it is difficult to comment with confidence on the remainder of the draft document.

The forum concluded that the community should be widely consulted on the revised Charter and the document which articulates the processes before they are adopted by Government.

The forum identified some specific comments on the current draft documents that might be useful in the review process and these comments are recorded below.

## **Specific comments on the draft Charter**

### **Definitions**

The Forum identified some specific issues relating to the definitions provided on page two of the draft Charter:

- ❖ **Consumer:** The draft Charter does not give a clear definition of “patient”, just “consumer”. The use of the term “patient” in the context of a “Public Patients’ Hospital Charter” is appropriate. The use of the term “patient” in the context of community support services is not.
- ❖ **Services for people with a disability:** The inclusion of people with disability and those who are ageing, with respect to those community based services that have been established to meet their support needs is inappropriate. If the intention is to cover (Health and Community Care) HACC services because that Program is administered by ACT Health, then that should be stated. However, there was a view that even this is inappropriate because;
  - People with disability and people who are aged are not sick, ill or unwell, merely because they have a disability or are old; and
  - The application of the medical model paradigm to services intended to enable people in these circumstances to live in the community is not appropriate and works against legislative, policy and community expectations.

There are some omissions in the groups defined within the document:

- ❖ The status of **family-carers**, especially with respect to people with disability or who are ageing, needs clarification.
  - Specific comments about family-carers should be included in the document where appropriate, even if it is to state that family-carers have no rights or responsibilities on a particular matter.
  - Under definitions of services for people with disability/aged people, these include services for carers. As carers are the consumers of these types of services, discussants could only presume that the Charter would apply to them in these circumstances?

- ❖ **“Respite care”** has been omitted from the list of services. If respite care is included, who is the consumer? This also relates to the comments about “carers” made above.

Other issues of definition were identified:

- ❖ Definition of **“public”**.
  - The idea of “public” is not used consistently in the document, and even in the same sentence. For example, in “Definitions: re “health service”:- “It also refers to public services for aged people and services for people with a disability”. There are numerous similar examples throughout the document.
  - In addition there could be confusion on the difference between public and private patient.
  - Are private hospitals included?
  - What happens if you are a public patient in a private hospital, and vice versa?
  -
- ❖ What does **“active and real involvement”** mean in the Preamble? “Involvement” should be defined to specifically state not just a “presence”, but also the opportunity to influence and capacity for self-determination.

### **Style and language**

- ❖ The revised Charter needs to include **references/footnotes** to relevant research findings, legislation, other policy documents etc.
- ❖ The **language** used in the draft Charter appears very general and articulates some ideal or “motherhood” propositions. Forum discussants would prefer that it be revised to enable the health consumer to have “sovereignty” over their health care (see comments about “active and real involvement” and “participate” below).
- ❖ The revised Charter needs to be written in **plain English**, (and be made available in other formats and community languages).
- ❖ There should be a **briefing document** which indicates how the revised Charter will be used, made available, disseminated and so on.
- ❖ The **current order** of the principles, and the dot-points within the principles, creates confusion. Possibly this can be overcome by a briefing paper, identifying for example that access to information has its own principle, and therefore is not included in all the other principles. That is, fair access to information is a “given”. Alternatively, comments that refer to access to information, non-discriminatory practice and so on, should be included in all relevant principles.
- ❖ Once finalised, the Charter needs to be made available in a **variety of formats and community languages**.

## Comments on the Principles

### **Principle One**

- Amendment to first dot-point: “..... equitable access to SAFE services...”
- Remove “where possible” from first dot point.
- Add dot point to make reference to non-discriminatory access.

### **Principle Two**

- Add a reference list of the relevant legislation for second dot point.
- “Financial matters” needs clarification. For example, how might “financial matters’ compromise or restrict patient’s access to a care or treatment option”? What is the implication for Principle One?
- Include reference to Auslan where interpreters are noted.
- Include statement that cost of interpreters will be met by the health service.
- This principle needs to emphasise the importance of full and comprehensive information provided at the appropriate time, and (where possible) with sufficient time to consider, research options and make an informed decision.
- The information gathering process needs to include not just “appropriate questions”, but also appropriate timing and in an appropriate manner, for example, culturally appropriate.

### **Principle Three**

There are a number of concerns about this principle, with a general view expressed that it is couched in patronising language and seems to underestimate the emotional and stressful situation people in hospital can experience, even when they have not been diagnosed with a mental illness or have a cognitive impairment.

The second dot point in the second paragraph (regarding clear the standards of behaviour...etc) should be deleted. This is a values based statement which appears to be targeting certain consumer groups, and in doing so:

- abrogates the responsibility of the employer to appropriately staff health services: -
  - with respect to **sufficient numbers** of staff
  - who have been **appropriately trained**
  - and are **adequately supported** to work with people from such consumer groups; and
- the importance of staff making **appropriate career choices**, that is in determining that they have the **appropriate attitudes** to work with people whose health or life experience results in them exhibiting “challenging behaviour”.

The third paragraph is also of concern for the reasons as discussed above.

The fourth paragraph should only require consumers to disclose "relevant" information. This again relates to the stigma and discrimination some people experience when disclosing certain health or other conditions.

#### **Principle 4**

- This principle needs to include a statement about the rights and responsibilities of family carers of people with disability or older people
- Health service staff should also **facilitate** referral to other services;
- First dot point, second paragraph - 'to the best of their ability' needs clarification, for example regarding people with disability, their family carers and others.
- Third paragraph, (Providers of health services...) "address factors" needs clarification.
- Again, health service providers should **facilitate** referrals;
- Clarify "important information" and query as to whether all relevant information should be available in writing?
- Finally, providers should **listen** to the information provided by consumers (and their family-carers where appropriate), take the time to assure themselves they have understood what they have been told by the consumer, and to assure the consumer that they (the consumer) has been heard.

#### **Principle 5**

- The first dot point in this section needs to be establish a right to an advocate of their choice and not be qualified by "as necessary" as in the right to an interpreter.
- Again the status of family-carers needs specific mention here.
- The whole approach to this principle should:
  - place the onus on the provider to offer, inform and so on, not on the consumer to a) know about something, and b) request it, whether it be for an advocate, interpreter, information, etcetera; and
  - the consumer's decisions are followed, except when there are clear not to. (Currently this is the second last dot point under the second paragraph. It should have a higher, over-arching priority. References to self-determination should be included.)
- Specific information needs to be provided regarding the "legal duties on providers" (for example, Tribunal decisions and so forth) at the beginning, not end of the principle.
- Consideration should be given to removing the last two dot points in paragraph one to the principle on research. There also needs to be information available to consumers on what generally happens to these substances.
- The second paragraph must emphasise the need for full information, provided in a way (enough time, at an appropriate

time, environment, culturally appropriate and so on) to facilitate informed decision making.

- The second dot point, second paragraph should clarify it is information about the provider's skill/competency level;
- This paragraph should also include information on people's rights to appeal orders etcetera (for example, regarding "legal duties on providers"), and facilitate access to an advocate, legal aid or other support service as requested.
- The third paragraph should require the provider to ascertain and document what, if any, steps have been taken to find a personal representative before taking action, and to not take any action unless these steps have been taken to find a personal representative;
- The third paragraph should start by clearly articulating the person is regarded as being competent to make decisions unless there is evidence to the contrary.
- How is the fourth paragraph to be implemented? In whose opinion? What is "appropriate"? Attitudes and community prejudices are a major influencing factor.
- A dot point should be added to the fourth paragraph to state that providers have a responsibility to confirm, and seek informed consent to a level of the person's competence/capacity (for example, from advocates, support services, family and so on).
- The fifth paragraph needs to spell out how the provider will "take reasonable steps", for example, via an advocate, family, or support services.
- Current options need to be specifically mentioned, for example "advance directives", "living wills" and so on.

### ***Principle 6***

- See previous comments regarding body parts and substances.
- What is the definition of a "student"? For example does this refer to a Junior Doctor?
- Needs to articulate this is an individual notification, not a sign in the foyer of the hospital saying "this is a teaching hospital and patients may be treated by ...etc"
- What is a teaching exercise? For instances, does this include general rounds or being invited to participate in a case study in a lecture?

### ***Principle 7***

- Please see comments at the beginning regarding strengthening this principle by including the concept of sovereignty, self-determination. This needs to be more than just participation through presence.
- Rewrite last dot point first paragraph (regarding advocate) and replace with "the assistance of an advocate when requested"
- Principles 5, 7 and 8 are related and need to be located together in the Charter.

- The right to privacy also needs to be included here, or a reference to that principle included.

### ***Principle 8***

- Needs to start out with an emphatic statement that providers will not disclose information without the consumer's consent, then go onto emphasise that where information is being provided without consent, the legal right to act is confirmed before hand, and the rationale is documented.
- Need to emphasise the obligation on providers to facilitate the right of consumers to access their information.
- The rights of family carers, if any, need to be included here;
- Need to emphasise the importance of providers identifying what information might be disclosed and to whom and for what purpose.
- It is important that this disclosure happen well before any treatment, and be included in the general information about options and consequences of treatment and so forth.
- People should also be informed of their appeal rights where their information is being given to others without their consent.
- Where information has been given to someone else without consent the person should be informed of what information, to whom, when and for what purpose.
- A separate section should be developed for electronic health records.
- This whole charter should be regularly reviewed, and special attention should be paid to this principle as information technology etc is changing access to, storage of, and the ability to widely disseminate information (possibly to unauthorised persons) at a rapid rate.
- Needs to state how long health records are retained and how those records are destroyed.

### ***Principle 9***

- Add "treatment" before "care" in second line.
- Is the word "not" correctly included here? If yes, then more information needs to be provided, and emphasis changed. That is, **will** have access to their health records except under these (identified) circumstances.
- "Copies" should also be included;
- Electronic records should also be included here.
- Whose health record is it?

### ***Principle 10***

This section glosses over the fact that feedback is subjective. Therefore the comments regarding "fair, truthful and accurate" are inappropriate. If the complaints process is fair, robust and transparent, the process will identify any issues of this nature. This approach engenders an attitude

that consumers must first “prove” their complaint is “fair, truthful and accurate” before the service takes it seriously. This is not acceptable under best practice complaints management processes. It loses an opportunity to improve one’s practice, irrespective of whether a “complaint” is substantiated.

- The second paragraph should be deleted.
- The first dot point under the third paragraph should be about open disclosure, that is, the provider should immediately inform the consumer when there has been a “mistake”, not wait for the consumer to come to the conclusion based on symptoms, etcetera.
- The principle should make reference to the ACT Health Consumer Feedback Standards, and the principle and process should be that standard.
- Right to/access to an advocate should be included early in the principle.
- External complaints bodies should be included;
- People should be kept informed about what is happening to their complaint, transparent process, timeliness and so forth.

## **Consultation process**

Discussants at the forum expressed some concern about the consultation process used for this policy and noted that access to the draft has been difficult even via ACT Health’s website. ACTCOSS and HACC would appreciate clarification about how agencies were informed of the draft Charter and how requests for feedback were made.

In keeping with the general consultation standards outlined in the *Community Engagement Manual* (published by the Community Engagement Unit, Department of Disability, Housing and Community Services, 2005) we would like further information about the next stages of the Charter development process including details of how these comments will be incorporated.

ACTCOSS and HCCA consider that the comments above are significant and further consultation with the community on the redrafted Charter is warranted before the final version is adopted by the ACT Government. We would be pleased to provide further input into the development of the Public Patients’ Charter and thank you for the opportunity to provide comment on this first draft.