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FEEDBACK ON DRAFT NATIONAL PATIENT CHARTER OF RIGHTS

Health Issues Centre

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Health Issues Centre welcomes the opportunity to give feedback to the Australian Commission on Safety and Quality in Healthcare (the Commission) on the Draft National Patient Charter of Rights.

Health Issues Centre (HIC)

HIC has been an independent, not-for-profit organisation for over 22 years, promoting consumer perspectives in the Australian health system. Its mission is to improve the health outcomes for Australians, especially those who are disadvantaged. It works with a wide range of consumers, health providers, researchers, governments and other health organisations to achieve this through:

- policy analysis and advocacy from consumer perspectives;
- consumer-focused research;
- supporting consumer participation; and
- providing information.

Health Issues Centre has a Board of Governance consisting of consumers as well as health professionals, managers and researchers. The Centre's focus is mainly in Victoria but is also national where appropriate.

Consultation

Please note that, due to limited timeframe for the consultation (5 weeks only), Health Issues Centre was unable to consult more broadly with consumers and community members who are members and partners of this organisation. We would have liked to have included their perspectives too on the meaning and usefulness of such a National Patient Charter of Rights. It is a pity that more time could not have been found to enable more inclusive engagement with consumers, carers and community members on this critical development

The following observations and comments are based on the historical and on-going dialogue and work Health Issues Centre has carried out over the past 22 years with consumers and community members in Victoria on health rights and quality and safety priorities. We have responded only where we feel we have sufficient experience and expertise.

1. National Patient Charter of Rights and National Patient Charter Principles

Overall comments:

It is clear that the Safety and Quality Commission have focused on this as 'Patient' Charter.

Health Issues Centre does not use the term 'patient' to encompass the experience of people trying to access health services and/or those currently using health services. 'Patient' is a 'medicalised' description of the individual and their relationship to the health service. It is a term that is more readily used for people in hospital care.

Health Issues Centre's concern is heightened because we are aware that the wish to develop this Charter to be all encompassing across all health services - including primary and community health.

From our work at the community health level, we are aware that many service providers do not define the people they are providing services to as 'patients'; they instead call them 'clients'.

This is problematic. There is a strong possibility that health care service providers at the community/primary health level may not see this Charter as relevant to their practice.

Health Issues Centre also wishes to point out that the discussion paper has used the term 'consumer' twice - on page 2 and page 11 of the Consultation Paper. Health Issues Centre is unclear what the Commission means by this term and why this inclusion in those statements. The term seems redundant in the context it is used; the Commission seems to have already decided to focus on the initiative as the 'patient' Charter.

For example, on Page 2 '*A national patient charter of rights will accordingly underpin the provision of safe and high quality health care and support a shared understanding of the rights and responsibilities of patients, consumers and health care providers.*

What does the Commission mean by 'consumer' here?

Health Issues Centre suggests that the use of the term may create confusion; if used, it will need to be clarified. What is the difference of 'consumer' and 'patient' in this context?

Whether the existence of both the Charter and Principles is useful

Health Issues Centre believes that it is useful to have both documents/statements. Our experience in working with both consumers and community members and health care service providers is that a broad statement of rights is made meaningful when it is more clearly defined in terms of direct practice and service delivery implications.

Health Issues Centre recognises that this is what the Commission has worked towards.

Health Issues Centre acknowledges that the Commission has developed a table to explain patients rights in terms of what patients can expect from the health system. Health Issues Centre notes the table on page 5. We believe that such a table may also be useful for health service providers. What does it mean directly for service providers that patients have these rights? Health service providers are 'the other side

of the coin' - and it may be useful to articulate those directly to health care service providers in relation to their practice. It is not just what patients are entitled to but it is about what health care services and all staff have the responsibility to provide and do.

Suitability of the Charter and principles for use by patients and providers

The Commission has made it clear that the Draft Charter describes what a patient is entitled to expect.

Health Issues Centre's contribution to this question about suitability is that such a charter needs to be developed and trialled with 'patients' across the spectrum of diversity that the Charter acknowledges is the basis to Australian society. If this has already taken place, then further comments are not relevant.

However, from Health Issues Centre's reading of the consultation paper, it seems that this key process has been missed. Much work has been already been done on preparing and communicating health information with patients and health consumers. Health Issues Centre recommends that the process of refining the language and explanation of these rights is done so using these evidence-based methodologies.

2. Rights included in the Charter

Whether the rights included in the Charter are sufficient to cover the range of patient and human rights

The extent to which the rights represent patient concerns when receiving health care

The above two questions have been answered concurrently under some of the key 'rights' described below:

Respect

Health Issues Centre recognises the importance of 'respect' as a separate key right within the Draft National Patient Charter. From the perspective of many consumers and community members this is core to the relationship they need from health care providers.

Health Issues Centre raises the question about the term 'consideration' as part of the right of respect. It is unclear what this really means.

It is relevant to note here the experience of Victorian consumers who attended the Australasian Safety and Quality Conference in Brisbane in 2007. They returned from the Conference inspired by the need to (re-)build compassion as part of the relationship from health care providers. Similarly a review of 19 studies of what consumers seek from health care providers rates 'humaneness' as the overriding characteristic of good quality care¹. Health Issues Centre proposes then that the Commission consider -

Respect: Respect, dignity and 'compassion'.

¹ Wensing, 1998.

Communication

This needs to be strengthened, especially in relation to communication with people from culturally and linguistically diverse communities and with people with 'limited' literacy and language skills.

Many health services are also working towards building and strengthening relationships with broader groups and communities of people beyond their 'period of care'. It is related to questions of equity of access and health promotion. Communication (And relationship building) is central in this work.

The explanation then here should not be focused only on individual level care, nor defined in terms of illness as the 'period of care' implies.

Health Issues Centre is particularly concerned with how the principle of communication is defined, especially in relation to the provision of interpreters.

Participation

HIC has a high level of expertise in processes of promoting participation in health.

The definition as it stands now is limited and not complete.

Firstly, participation is not only about informed consent, informed decision-making and informed choices. It is also about informed and **shared** decision-making. It is based on the process of the communication and relationship between health care provider and patient.

Secondly, the existing explanation here only refers to participation at the individual level of care. Patients have a right to participate at all levels of decision-making in the health service - from the individual; to programme and service levels, including planning, development and evaluation and at the organisational level, including defining the priorities of the strategic plan and policies. The following statement from the International Alliance of Patients' Organizations (IAPO) summarises this point:

The IAPO calls on all stakeholders in healthcare to include patients in a meaningful and sustainable way in all levels of their work and at all points of decision-making, and to build on existing models of involvement in collaboration with patients around the world. "To meet patients' needs, decisions that affect a patient's healthcare should not be taken without the full involvement of the patient at all levels of care, whether that be in the choosing of treatment options, developing healthcare policy or designing healthcare systems."

Myrl Weinberg, IAPO Chair and President of the National Health Council (USA).

It is critical that this Draft Charter of Patient Rights reflects these levels of participation in decision-making.

Privacy

There is an additional element to privacy that must be considered and integrated here.

It is important not only that personal information is secure but that personal information is only made available between health workers and health services at the consent of the patient.

3. Points included in the principles

Whether the explanations included in the Principles assist in understanding the rights and responsibilities of patients and providers

The extent to which the rights represent patients concerns when receiving health care

Communication

The first principle under communication is limiting.

Firstly it is limited to the period of care. Above, in Section 2, this point has already been explained. Communication between health services and patients take place in a multitude of places and circumstances and it is not always related to direct care. Secondly, the second part to this first principle is also of concern. It reads 'particularly when plans change or if something goes wrong.'

This seems to focus on the open communication at a certain point in time rather than it being integral throughout the entire relationship between health care provider and patient.

Perhaps the word 'particularly' can be changed to 'including'. Or more appropriately, a separate statement can be made here in relation to open disclosure.

Thirdly, Health Issues Centre expresses grave concern about the third principle described under communication that of

'access to a qualified interpreter, where possible'.

A patient charter of rights should be explicit, to be effective in protecting and advocating for the rights of patients and must declare such rights unconditionally. This principle should read - 'access to a qualified health interpreter in all circumstances where necessary' - without this statement the safety and quality of care to patients is compromised.

Information

Health Issues Centre recognises the principle identified in the Charter on the 'need to explain the difference between accessing public hospital services as public or private patient.' In the research that Health Issues Centre has carried out, there is confusion about this for many patients.

Participation

Health Issues Centre repeats the concern here that was expressed in Section 2. The foci of the principles are mostly about participation at the individual level.

This is a critical limitation of the principles. Here the Charter can give strong direction to health services about definition of participation at all levels of the health service - individual level programme/service/ward level and organisational level.

Health Issues Centre's experience is that this also helps health services understand the complexity but also the process of opening up patient participation.

Health Issues Centre also reminds the Commission of the need to consider 'how' the Charter is to support patients to empower them to obtain the best possible care.

The process of empowerment is a complex process.

Health Issues Centre recommends that the reading of the first principle under participation include the following:

'To be encouraged and appropriately supported to be involved in decision making in their own treatment and care and in the services and policies developed by the health services'.

We trust these comments are valuable. We would be happy to discuss them further with you.