Naomi Poole
Director, Partnering with Consumers
Australian Commission on Safety and Quality in Health Care
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Dear Ms Poole

Re: Consultation on the Australian Charter of Healthcare Rights

The Health Care Consumers' Association (HCCA) is a health promotion charity and the peak consumer advocacy organisation in the Canberra region. Last year we celebrated forty years of incorporation. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation, and consumer and community consultations,
- training in health rights and navigating the health system,
- community forums and information sessions about health services, and
- research into consumer experience of human services.

HCCA is a member-based organisation and for this submission we consulted with HCCA's Quality and Safety Consumer Reference Group and our Health Policy Advisory Committee.

Thank you for the opportunity to put forward consumer views on the new version of the Australian Charter of Healthcare Rights.

Yours sincerely

Darlene Cox
Executive Director
13 March 2019

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HCCA Response:
Consultation on the
Australian Charter of Healthcare Rights

Submitted 12 March 2019

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Executive Summary and Recommendations

HCCA values the Charter of Healthcare Rights as it articulates the key elements of high-quality healthcare for consumers

HCCA's consultation on the revised Australian Charter of Healthcare Rights clearly indicated that articulating healthcare rights is important to consumers. We believe that the overarching right to health care is the right for consumers to high quality care. As such, we make the following recommendations:

1. That 'Quality' be added to the Charter of Healthcare Rights as the first and overarching right.
2. That the Commission consider HCCA's feedback when finalising the wording of the Charter and the detailed descriptions of each healthcare right.
3. That a supporting brochure or booklet for consumers be produced on the Australian Charter of Healthcare Rights that explains each of the rights in detail, as well as what they might look like in practice.
4. That the Commission create culture, language and orientation specific versions of the Charter and accompanying explanatory material, especially for the original inhabitants of Australia and those from culturally and linguistically diverse backgrounds. It is also desirable that versions be created that speak to the needs of populations whose needs are not routinely well met by health care services (e.g. people with disabilities, Lesbian, Gay, Bisexual, Trans and Intersex (LGBTI) people).

Feedback on the draft Charter of Healthcare Rights

HCCA welcomes the opportunity to provide input to the draft Australian Charter of Healthcare Rights. As an advocacy organisation, we have a strong interest in the Australian Charter of Healthcare Rights as they underpin our work in systemic consumer health advocacy. We acknowledge that the Charter is an evolving document and encourage the Commission to revisit it regularly. We also acknowledge the inter-related nature of the rights.

For a long time, quality was believed to be the natural outcome of a sound medical education and the good intentions of medical practitioners. And while everyone agrees that we want quality health care, there is little evidence that key stakeholders have a shared understanding of the concept.[1] This document explicitly speaks to consumer rights. However, we acknowledge that both those receiving the care and providing the care have responsibilities.

Quality health care from a consumer perspective means an increased likelihood of desired outcomes consistent with their wishes and a reduced possibility of undesired outcomes.[2,3] Furthermore, HCCA believes that quality is a multivalent concept and what is included depends on one's definition. We like the six dimensions proposed by the World Health Organization (WHO) – effectiveness, efficiency, accessibility, acceptability to the individual, equity, and safety.[4]

Any charter of healthcare rights exists to ensure that consumers receive high-quality care. The current and draft Australian Charter of Healthcare Rights includes access, safety and partnership. However, we feel strongly that the right to high-quality care needs to be highlighted. This is best done by including it as a healthcare right, indeed, the primary one! All the rights listed in the draft charter are important, but they exist to ensure that consumers receive quality health care.

Following our consultation with consumers, we provide detailed comments below on each of the rights of the draft charter.

We would also like to note that while the brief form of the Charter of Healthcare Rights (as set out in the draft we received for comment) is appropriate for products such as posters placed around healthcare facilities, there is also a need for a brochure or booklet that explains each of the healthcare rights in more detail. This could help consumers to better understand what each of these healthcare rights means in practice. This is one way to improve health literacy[5] and empower consumers to not only know their rights in healthcare but to be proactive in ensuring these rights are demonstrated in their care.

In finalising the Charter and any accompanying material, it is important that tautologies are avoided. At present,

- “Access” is described as the “right to *access* services and treatment”, and
- “Respect” is the “right to be cared for as an individual and treated with dignity and *respect*”

Feedback on individual healthcare rights

Access

The term “access” raised much discussion among our consumers. As stated above, the sub-point provided to demonstrate the “right to access” used the term “access”, which does not illuminate its meaning. Furthermore, consumers were very clear that the term access can mean many different things. For instance, access can refer to one, or some combination, of the following:

Awareness

- Is the person aware of a service?

Information

- Is the person able to easily locate the information they need about a service?
- Does the information make sense to them, or do they have the assistance they need to understand the information?
- Does the information provide sufficient information to help them make a decision?

Affordability

- Can the person pay any associated cost, especially when accessing private services?

Availability

- Is the service offered in the local area?

Timeliness

- Can the person get an appointment easily?

Location

- Is parking or public transport is easily available?

Manoeuvrability

- Is the service able to be negotiated by a wheelchair or elderly person, for instance?

Receptivity

- Will the person be listened to and responded to appropriately?

Culturally appropriateness

- Do people from Indigenous or culturally and linguistically diverse backgrounds feel comfortable using the service?
- Are interpreter services available?
- Are liaison officers available?

Safety

The term “safety” also generated much discussion in our consultation with consumers. Consumers told us that just because care is safe, it doesn’t necessarily mean that it is of high quality nor that it is appropriate (e.g. surgically removing the wrong leg). While they felt that safety was a dimension of quality, the overwhelming consensus was that it was still useful to include safety as a separate right. Consumers acknowledged that safety is a term that particularly engages clinicians and focuses on clinical care.

There was concern that the sub-point to “receive care in a safe environment” was too passive. A suggested replacement for “receive care” was to “be cared for”. There was positive feedback around the idea that care should be both culturally and clinically safe for consumers.

Respect

Consumers were positive about “respect” as a right, and thought that overall, the sub-points explained what is encompassed by this term in healthcare. However as stated earlier, it suffers from using the same term to illuminate the meaning of that term. Alternate words that could be used include recognise, respect, show consideration. Our consultation highlighted that dignity was an important part of defining respect.

Partnership

The proposed right of “Partnership” – replacing “Participation” from the previous version – is a welcome change. In our consultation, consumers felt very positively about using the term “Partnership”. They felt that partnership better encompasses the concepts of shared decision making and consumer-centred care. Consumers also told us that they really liked the idea that in a partnership one can include the people one wants in planning and decision making. This concept is embedded in the national standards and we support consistency across the Commission’s documents.

Information

Consumer were negative about the term “information” because it was too one-way. Communication remained their preferred term. One consumer suggested that while clinicians have a moral obligation to communicate information to consumers, it should be clear that consumers have the right to use this information to ask questions of their health professionals and to use information to make their decisions.

There was particular concern about consumers being properly engaged and informed at the time that something goes wrong, as well as being part of the resolution. The current sub-points do not seem to express the right to open disclosure[1]. While “open-disclosure” is not a term consumers necessarily use, they nevertheless want it to happen.

Privacy

This term was acceptable to consumers, although there was some concern that perhaps the sub-points did not sufficiently explain what might be encompassed under this right. Consumers raised the various aspects of environmental privacy (e.g. sight, sound) and the need for personal space that need to be conveyed. This term will likely need more practical explanation in an accompanying brochure or booklet.

Give feedback

Consumers felt that the terminology for this right was a great improvement on the right to “comment”. The right to “provide feedback, either positive or negative, or to make a complaint without it affecting the way that I am treated” was particularly important to consumers. This definition of giving feedback helps consumers to feel that they can be honest and contribute to service improvement, without fear of repercussions.

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[1] Open disclosure is the open discussion of adverse events that result in harm to a patient while receiving health care. This is not a one-way provision of information, but a discussion and exchange of information that may take place in several meetings, over a period of time, and may include any combination of the patient, their family and carers (Australian Open Disclosure Framework, ACSQHC 2013)

Concluding comments

Thank you for the opportunity to provide feedback on the revised Australian Charter of Healthcare Rights. HCCA looks forward to seeing how this consumer feedback in incorporated and we would be glad to discuss any aspect of our feedback in more detail.

References

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[1] *The Quality of Australian Health Care: Current issues and future directions.* Occasional Papers: Health Financing Series Volume 6, Prepared by M Fletcher, Department of Health and Aged Care, Canberra. 2000.

[2] Institute of Medicine (National Academy of Sciences), "Crossing the Quality Chasm: The IOM Health Care Quality Initiative". http://www.nationalacademies.org/hmd/Global/News%20Announcements/Crossing-the-Quality-Chasm-The-IOM-Health-Care-Quality-Initiative.aspx (Accessed 8 March 2019).

[3] See note (i)

[4] World Health Organisation. *Quality of care: A process for making strategic choices in health systems*. 2006. https://www.who.int/management/quality/assurance/QualityCare_B.Def.pdf (Accessed 8 March 2019).

[5] Health Care Consumers' Association "Health Literacy Position Statement" HCCA, Canberra. June 2017. https://www.hcca.org.au/wp-content/uploads/2018/09/Health-literacy-position-statement-FINAL.pdf (Access 11 March 2019).