

Professor Chris Baggoley
Chief Executive
Australian Commission on Safety and Quality in Healthcare
GPO Box 5480
SYDNEY NSW 2001

6 March 2008

Dear Prof Baggoley,

Please find attached National Breast and Ovarian Cancer Centre's submission on the draft National Patient Charter of Rights. We welcome the opportunity to review the draft document and support this important health initiative.

Please contact A/Prof Christine Giles on 02 9357 9404 or via email on christine.giles@nbocc.org.au should you require any further information about our response.

Yours sincerely



Dr Helen Zorbas
Director

NATIONAL PATIENT CHARTER OF RIGHTS

National Breast and Ovarian Cancer Centre (NBOCC) is Australia's independent national authority and information source on breast cancer and ovarian cancer. Funded by the Australian Government, NBOCC works in partnership with health professionals, cancer organisations, researchers, governments and those diagnosed to improve outcomes in breast and ovarian cancer.

Since its inception, NBOCC has pioneered an innovative approach to the translation of evidence into practice through extensive collaboration with stakeholders. This collaborative model, where the program of work is both informed by and responsive to consumer (patient) needs, has led the way in patient engagement in Australia.

NBOCC supports the establishment of a National Patient Charter of Rights and welcomes the opportunity to review the draft document. This response will address relevant questions specified in the consultation paper.

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

The establishment of a National Patient Charter of Rights is an important step in developing a consistent approach to patient care in Australia. It is most important that patients are aware of what they are entitled to expect from the health system and that health care providers are aware of their responsibilities in delivering care.

We suggest that the existence of two separate documents covering the Charter in different levels of detail may be a cause for confusion. For example, a patient may be given a copy of the Charter, but they may not always receive the supporting Principles. Perhaps one document clearly outlining the rights of the patient that also includes suitable explanations and examples would serve as a more useful document ensuring both patients and health care providers have access to the same information.

NBOCC supports the use of clear, accessible language in the document, as health care consumers have wide ranging levels of literacy. Perhaps language that speaks directly to the patient e.g. 'You have the right to...' or 'I am entitled to...' would be the most engaging way to express all aspects of the Charter and its supporting Principles to provide more meaning for the individual. NBOCC works extensively with people from culturally and linguistically diverse backgrounds and would support the availability of the final Charter in a range of languages and in a form appropriate to Indigenous Australians.

2. Rights included in the charter

NBOCC supports the eight patient rights covered in the Charter. NBOCC's world-first *Clinical practice guidelines for the psychosocial care of adults with cancer* support the importance of the inclusion of 'Communication', 'Information' and 'Participation' in the Charter. The evidence indicates that the way a treatment team relates to and communicates with a patient can significantly benefit the patient and their family, including improvements in psychosocial adjustment, decision-making, treatment compliance and satisfaction with care. NBOCC supports and promotes evidence-based communication skills training for all health professionals working in cancer.

The quality of information provided to a patient is also important. Research indicates appropriate, detailed and individualised information promotes patient understanding and

increases the well-being of the patient. Additionally, evidence shows the way in which a prognosis is communicated to a patient influences a patient's decisions about treatment. We would suggest the Charter promotes the right to quality information, preferably evidence-based information where available.

NBOCC supports the inclusion of 'Safety' in the charter. We suggest that the explanation of 'Promoting safe and competent care' could be extended to include a focus on observance of quality standards or access to high quality health services as featured in the European Charter of Patients' Rights.

There is also an opportunity to include specific reference to a patient's psychosocial care. Evidence in this area indicates a cancer patient's emotional wellbeing is just as important as their physical wellbeing in determining quality of life. Perhaps reference could be made to a patient's right to have emotional, psychological and social support in addition to physical treatment throughout their encounter with the health care system.

3. Points included in the Principles

NBOCC supports the level of detail provided in the accompanying principles, but as previously mentioned; it may be more practical and meaningful to include all the information in one document rather than separating the Charter and Principles.

4. Rights and responsibilities

The Charter and Principles are based on the understanding that there are responsibilities for both patients and providers. However, specifically stating the responsibilities of the patient (as many of the State Charters do) may be a more effective way of promoting this component of the Charter and therefore a partnership between the patient and the treatment team. Areas of responsibility for the patient may include:

- treating all people with care, dignity and consideration
- providing medical staff with a complete and honest medical history
- asking for further explanation if you don't understand what you have been told
- informing medical staff if you vary from your treatment regime
- informing medical staff of any changes to your condition
- discussing with medical staff any complementary or alternative treatments you are considering.

5. Existing charters

As a national organisation, NBOCC supports the establishment of a national, uniform approach to ensuring patient rights and responsibilities are promoted and upheld.

6. Possible uses of the charter

NBOCC supports the role of the national Charter in providing a unitary agreed set of principles to be adopted or to guide the review of existing State/Territory or local charters. NBOCC agrees that the development of the national Charter is an opportunity to raise the profile of patient rights and responsibilities, as well as the responsibilities of health service providers. All health care providers should be aware of the existence of the national Charter and perhaps its content could be incorporated into student training across all health disciplines or be included in continuing professional development.

7. How the charter applies in different sectors and settings

The level of detail provided in the Charter and accompanying Principles achieves its aim of being relevant across all health care settings. There is an opportunity for specific health care settings or patient groups to develop tailored examples relevant to their context based on the guiding patient rights and principles set out in the national Charter.

National Breast and Ovarian Cancer Centre welcomes the establishment of a National Patient Charter of Rights and is appreciative of the opportunity to have input into this important health initiative. NBOCC supports endorsement of the Charter by all Health Ministers and looks forward to seeing the final document.