

Breast Cancer Network Australia
Submission to Consumers Health Forum
Our Health, Our Community Project Consultation Paper

28 February 2011



About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We empower, inform, represent and link together people whose lives have been affected by breast cancer.

BCNA represents more than 52,000 individual members and 284 Member Groups from across Australia.

BCNA works to ensure that women diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible – no matter who they are or where they live. BCNA is represented by the pink lady silhouette. The pink lady depicts the organisation's focus – women diagnosed with breast cancer.

Submission

Breast Cancer Network Australia welcomes the opportunity to provide a submission to CHF's *Our Health, Our Community Project* consultation paper.

We note the purpose of the consultation paper is to receive feedback about:

- the information needs of consumers to help them navigate the health system
- how consumers would like to have a say on health reform
- the training and support needs of consumer representatives working on high level governance structures of the National Health and Hospitals Network (NHHN).

Information needs of women with breast cancer

BCNA has undertaken research with our extensive membership over recent years to learn about the types of information women want to assist them through their breast cancer journey.

With regards to information about navigating and using the health system, our members have told us that they seek information on:

- managing the costs of health care
 - access to early superannuation payouts (for those with a terminal illness)
 - assistance with meeting mortgage payments while undergoing treatment
 - bulk billing
 - Medicare and the Medicare Safety Net
 - Public v Private health care – benefits and disadvantages in terms of cost, treatment and care

"There needs to be more information on how you can stay financially stable during such a tough and expensive time."

A network of support for Australians affected by breast cancer

Patron: Her Excellency
Ms Quentin Bryce AC,
Governor-General of the
Commonwealth of Australia

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- resources and practical support available for women in rural and remote parts of Australia
 - travel assistance
 - accommodation
 - local services, eg home help
 - accessing Breast Care Nurses and/or a multidisciplinary team
 - accessing allied health service practitioners
 - peer support (other women, groups)
 - advice on whether local medical services are comparable with those offered in major centres
 - specific resources and support for women from Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander backgrounds

All (rural) women need to know about the transport and accommodation support through their local hospital system, how to access the forms and complete them. At times there is financial assistance available although this is not universally available. They should be empowered to ask whether there is a welfare officer/ social worker who can help them access locally available support.
 – Marion, Breast Care Nurse

- resources and support for partners, family and friends
- how to get the most out of medical consultations
- surgery
 - what to take to hospital
 - returning home
 - how to access breast reconstruction – public v private
 - how to access breast prostheses and post-surgery bras
 - lymphoedema – prevention, management and how to access compression garments
- the process for approving medications for use in Australia (Therapeutic Goods Administration)
- the process for listing of medications on the Pharmaceutical Benefits Scheme, including why some breast cancer medications are listed and others not (Pharmaceutical Benefits Advisory Committee)
- the process for listing of medical technologies and procedures on the Medicare Benefits Schedule (Medical Services Advisory Committee)

With regard to health reform and the NHHN, BCNA believes information about the impact of health reform on consumers should be available and easily accessible to consumers, and should include information about:

- how the new health system is different
- what difference consumers will see in the way health services are delivered
- what consumers need to know about accessing health services under the NHHN
- what the benefits of the reforms are for consumers
 - more hospital beds?
 - more nurses?
 - shorter waiting lists for surgery in public hospitals?
 - reduced out-of-pocket costs?
- what the disadvantages of the reforms are for consumers
- information to help them make decisions about private vs public care

Having a say in health reform

BCNA believes interested consumers can and should have a say in health reform through

- online surveys such as those included on the CHF website as part of this consultation process
- consumer organisations such as BCNA
- being invited to provide feedback following the provision of a service (eg hospital procedure) through the NHHN

A marketing strategy may need to be put in place to ensure consumers are aware they can contribute to this process.

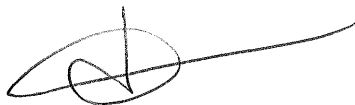
Training and support needs of consumer representatives

Through our nationally and internationally recognised *Seat at The Table* program, which has been used as a model for other groups, we know that the following is needed for consumer representatives to be effective:

- initial comprehensive training which allows them to develop skills, knowledge and confidence to sit on different committees and represent a broad experience beyond their personal view
- clear process to ensure that requests will aim to achieve improved outcomes for women and involvement is not tokenistic
- clear understanding of their role and expectations
- ongoing training to assist knowledge and confidence
- ongoing support that involves a clear process for everyone involved (opportunities and mechanisms to connect with their peers to share knowledge and experiences)
- clear process for feedback from consumers and organisations.

The training has given me more confidence, broadened my skills, understanding and awareness about breast cancer issues and advocacy. It has fanned the "fire in the belly".

Thank you for the opportunity to contribute to this review. For further information on our submission, please contact Kathy Wells, Senior Policy Officer, on (03) 9805 2500 or at kwells@bcna.org.au.



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