

**Breast Cancer Network Australia
Submission to the Department of Health and Ageing**

**Draft Concept of Operations: Relating to the introduction
of a Personally Controlled Electronic Health Record
(PCEHR) system**

27 May 2011



A network of support for Australians affected by breast cancer

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 57,000 individual members and 285 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 regarding the *Draft Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record (PCEHR) system* (Draft Concept of Operations).

As the peak national consumer organisation for women affected by breast cancer, the focus of this submission is to raise issues that have the potential to affect our membership. In 2011, approximately 14,200 women in Australia will be diagnosed with breast cancer.¹ There are approximately 140,000 women living in Australia, who have previously been diagnosed with breast cancer.²

BCNA supports the development of the PCEHR system and believes that it has the potential to enhance sharing of health information between individual health care providers, and between consumers and their health care teams.

This is particularly important for women with breast cancer, who may see a number of different health professionals as part of their treatment and care. Sharing information between these health professionals, and with the woman undergoing treatment, can be inefficient, time consuming, and problematic. This can particularly be the case for women in rural areas, who may travel hundreds of kilometres for medical appointments only to find that key records or pieces of information have not been transferred.

Patron: Her Excellency
Ms Quentin Bryce AC,
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¹ Australian Institute of Health and Welfare (AIHW). Breast cancer in Australia: an overview, 2009. Cancer series no.50. Cat. no. CAN 46. Canberra: AIHW.

² Ibid

'Breast cancer and its treatment has been only one of my medical ailments for which reports have had to be transferred interstate and backwards and forwards. Added to that, I am now in my seventies and have difficulty in readily remembering much of my medical history that relates to 30 or 40 or 50 years ago. I am looking forward to it [PCEHR] being on-line to all those who need to know. The fact that my history will be complete and available when needed in any medical emergency is of infinitely greater importance to me'- BCNA member

This submission will address only three issues relating to the PCEHR system, namely the:

- model of participation by healthcare providers and organisations
- process regarding the correction of errors
- long-term governance arrangements.

Participation by healthcare providers and organisations

As outlined in section 3.3 of the Draft Concept of Operations, participation by healthcare organisations and their associated healthcare providers in the PCEHR system is voluntary, not mandatory.

BCNA understands that the voluntary model of participation may be an effective and strategic move to encourage as many healthcare organisations and healthcare providers to participate in the system as possible, when the system becomes operational. However, BCNA is concerned that the continued opt in' model of participation for healthcare organisations and healthcare providers may undermine the potential benefits provided to consumers through the PCEHR system, particularly for consumers living in rural and remote areas of Australia. For example if a consumer's metropolitan based oncologist has chosen not to participate in the PCEHR system he or she will not be able to electronically share key health information about that consumer to other relevant health providers who are participating in the PCEHR system, and vice versa. In short, the non-mandatory participation of healthcare organisations and providers has the potential to weaken the benefit of electronic sharing of health information between healthcare providers and between consumers and healthcare providers.

BCNA believes that for the PCEHR to achieve its full potential of enabling access to, and the sharing of health information when and where it is needed by consumers and their healthcare providers; participation by healthcare organisations and providers should be mandatory.

Correction of errors

As outlined in paragraph 5 of section 4.6.1, the PCEHR System Operator will provide a process to help individuals with the correction of errors (in their PCEHR), in the event that they do not want to approach the healthcare organisation directly about the correction. We are concerned however that this process is not currently specified in the Draft Concept of Operations. We believe this should be set in place *before* the PCEHR system becomes operational to ensure that from day one of operation of the system, users will know how to correct errors and manage their own records.

Long term governance arrangements

While the Draft Concept of Operations acknowledges that appropriate governance structures and mechanisms are essential for the successful delivery of the PCEHR system, no detail has been provided about the

system's long term governance arrangements, other than to say that they will be underpinned by the following principles:

- Accountability
- Leadership
- Engagement
- Clinical viability
- Effectiveness
- Efficiency
- Integrity
- Transparency and Openness
- Sustainability

To provide individuals with some confidence about the long term governance of the PCEHR system, BCNA believes that more information about the arrangements regarding the long term governance requirements of the PCEHR should be confirmed, and made public *before* the PCEHR system becomes operational.

Thank you for the opportunity to contribute to this review. For further information on our submission, please contact Astrid Keir, Senior Policy Officer, on (03) 9805 2585 or at akeir@bcna.org.au.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'Michelle Marven', with a long horizontal stroke extending to the right.

Michelle Marven
Policy Manager