Breast Cancer Network Australia submission

Disclosure of genetic information to a patient’s genetic relatives under Section 95AA of the Privacy Act 1988 (Cth)

Guidelines for health practitioners in the private sector – Consultation draft

Breast Cancer Network Australia (BCNA) thanks you for the opportunity to contribute a submission on the 'Disclosure of genetic information to a patient’s genetic relatives under Section 95AA of the Privacy Act 1988 (Cth): Guidelines for health practitioners in the private sector – Consultation draft 11 February' (the guidelines).

This submission has been developed in consultation with BCNA members. Our submission focuses specifically on the implications of the guidelines for people with breast cancer, as our area of expertise.

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 26,000 individual members and 194 Breast Cancer 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.

Each year more than 13,000 women are diagnosed with breast cancer. Approximately 5% all breast cancers can be explained by an inherited gene fault in BRCA1 or BRCA2. It is estimated that approximately 40,000 Australian adults carry a breast cancer genetic fault. In addition, there are people with a strong family history of breast cancer who do not carry known gene mutations.

Introduction
BCNA supports the development of the guidelines, which provide clarity and greater detail to support the effective implementation of the recent amendments to the National Privacy Principles contained in the Privacy Act 1988 (Cth) (the Privacy Act).

Disclosure of genetic information to genetic relatives is a complex and challenging area both legally and ethically, and the development of the guidelines promises to provide a process and key strategies to assist practitioners. Health consumers are


likely to benefit from the guidelines as they encourage important strategies such as clear and ongoing communication with consumers initially and over time, collaborative decision making where possible, and active referral to family cancer centres.

**Guidelines for the public health and research sectors**

We appreciate that the Privacy Act does not apply to the public health sector, or to the Australian Government, or State and Territory agencies. We are concerned therefore, that there will be quite different requirements for health care professionals in the private system, compared with the public system as a result of the implementation of the guidelines. For health consumers this could mean poorer outcomes due to considerable confusion and lack of consistency as to which process is applied, in the event that they refuse to consent to the disclosure of genetic information. This could also be confusing for health care professionals, particularly those working across both the public and private health care systems.

It raises questions about whether there is a process that is currently applied in the public health care setting, and if there isn't, whether there are plans to undertake a similar amendment to the Information Privacy Principles. BCNA would support the development of complementary guidelines for the public sector. In the meantime the inclusion of a question on this issue in a ‘frequently asked questions’ section of the guidelines may be useful.

We are also concerned that there may be unintended consequences for family cancer centres as a result of the guidelines only applying to the private sector, as the centres are largely located within the public health system, and therefore not covered by the guidelines. This is of particular concern as liaison with, and referral to, these services comprise an important component of the guideline requirements, raising possible unintended consequences at the programmatic level.

For example, what are the pathways for health care professionals in the private sector to access information and support from family cancer centres, located in the public health system, when the guideline requirements do not apply to the centres? How can health care professionals in the private sector ensure timely access to these centres when referring consumers?

Although the scope of the guidelines does not include people who are participating in research, BCNA is concerned about which processes should apply to this group, regarding genetic information and disclosure to genetic relatives.

For example, a person may participate in a research project, but not provide consent to be contacted should relevant genetic information be discovered. If the research organisation finds information which is clinically relevant to a person, and his or her relatives, should the research organisation contact a specialist genetic service so that the ‘research’ information can be assessed and passed on in a ‘clinical’ setting? Should the research participant be thought of as a ‘patient’, and should similar guidelines then be applied in a similar manner? Should we assume that when a research participant signs a consent form to not be notified if information is found, that they are making an informed decision?

These are complex issues, and present significant challenges to those involved as to the best way in which to respond. Clear, applicable guidelines will provide clarity.
and consistency for health care professionals, researchers, family cancer centres, health consumers and research participants.

**Role of family cancer centres**
Family cancer centres can play a vital role in supporting health consumers and health professionals regarding a genetic diagnosis and subsequent decisions about notifying genetic family members.

While the guidelines include some reference to consultation with, and referral to, family cancer centres, BCNA would like to see this strengthened in the document. Family cancer centres provide a most valuable service in the area of breast cancer, including specialised counselling and the latest information on genetic issues.

Without the involvement of family cancer centres and their expertise, there is a considerable risk that consumers may not receive the most accurate or up to date information. They may also not be able to access the specialist support they

For example, a family history of breast cancer on paper may suggest a likely genetic mutation on one side of the family. However, following genetic testing it may be found that the genetic mutation is in fact on the other side of the family. A decision to withhold disclosure to family members until after testing would have vastly different consequences in this situation than a decision to disclose before hand, and support from a family cancer centre could be crucial in understanding this possibility and reaching this decision.

We therefore strongly support a modification of the guidelines to require health care professionals to always consult with family cancer centres in cases of breast cancer, where a consumer has refused to consent to disclosure, and to refer a consumer for further information, counselling and support. However, this should not preclude consultation by the health care professional with other professional experts.

As noted earlier, there is further work required to establish clear pathways for referral from the private sector to family cancer centres in the public system, to ensure timely access and support can be achieved.

**Role of General Practitioners**
BCNA also supports the inclusion of an additional requirement that General Practitioners (GPs) always be included as part of the medical care team regarding genetic information. GPs will generally continue to see the health care consumer on an ongoing basis, and may be able to encourage them to agree to disclosure to family members. They are also more likely to be in touch with other family members. This also reflects broader trends in health care to include GPs as a key part of a multidisciplinary approach to health care.

**Conclusion**
BCNA supports the development and implementation of the guidelines, however we would urge further consideration of the issues raised in this submission. We would welcome the opportunity to speak with you further regarding this submission, and thank you again for the opportunity to participate.

*Breast Cancer Network Australia submission*