

Privacy and Confidentiality Guidelines

For the **lifepool** project



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*In preparing these Guidelines, the **lifepool** project has specifically referred to the Peter MacCallum Cancer Centre Privacy Policy on Health Information Management (Version 2, issued August 2009), Chapter 5 of the 'Guidelines for Genetic Registers and Associated Genetic Material', NH&MRC 2000 (<http://www.nhmrc.gov.au/publications/synopses/e14syn.htm>) and Victorian Information Privacy Principles as part of the Information Privacy Act, Vic 2000 ([http://www.privacy.vic.gov.au/privacy/web.nsf/download/1DD5FF517C6D97E2CA256C520026BD33/\\$FILE/Schedule%201%20of%20the%20IPA%20.pdf](http://www.privacy.vic.gov.au/privacy/web.nsf/download/1DD5FF517C6D97E2CA256C520026BD33/$FILE/Schedule%201%20of%20the%20IPA%20.pdf))*

Background Information

The **lifepool** Project is a collaboration between the Peter MacCallum Cancer Centre, BreastScreen Victoria, the University of Melbourne School of Population Health and The Royal Melbourne Hospital. It is funded by the National Breast Cancer Foundation and aims to recruit 100,000 Victorian women over 5 years. Women will be asked to provide answers to a health and lifestyle questionnaire, allow access to medical information from several sources including mammogram results from BreastScreen Victoria and linkage with several large health databases. The information provided by participants in **lifepool** will provide a significant new resource for research. The **lifepool** Project is a resource open to access by all approved researchers, nationally and internationally. Data in a coded form will be supplied to approved research projects focussed on breast cancer and other women's health issues. Confidentiality is paramount to **lifepool** and the Data Management team will be responsible, along with the General Manager, for maintaining the **lifepool** electronic and paper-based records securely and accurately.

Our Obligations

The Peter MacCallum Cancer Centre (PMCC), as the Principal Institution, requires all staff working on the **lifepool** project to be aware of their obligations regarding the use, disclosure and access to confidential information collected and held by **lifepool**. These broad obligations are described in PMCC Privacy Policy: Health Information Management Version 2, August 2009

All members of the **lifepool** data management team must:

- Be appropriately qualified, skilled and experienced to carry out the functions of the **lifepool** resource.
- understand their obligations in regard to privacy and confidentiality and, in particular, to adhere to the Information Privacy Principles (IPPs) detailed in the Information Privacy Act, Victoria, 2000.

The way in which **lifepool** responds to the ten IPPs is summarized below:

1. **lifepool** will only collect personal information as detailed in the Participant Information and Consent Form.

2. **lifepool** will only use the information collected from or about participants for the purposes of approved research into breast cancer or other women's health issues.

3. All information will be kept as up-to-date and complete as possible. **lifepool** will carry out regular matching of data to other agencies (where possible, feasible and applicable) which can provide more accurate and up-to-date information on participants (eg. Victorian Cancer Registry)

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4. All participant information will be protected against misuse, unauthorised access, modification or disclosure. All databases will be protected by user authentication and adequate firewalls. Any transmission of data will be encrypted for security.
5. All **lifepool** policies dealing with management of personal information will be freely available and participants will be given a copy of the Information and Consent Form which clearly describes the information collected, the manner in which it is collected, how it is stored and who may access the information.
6. Participants can gain access to information collected about them at any time by appropriate request, but any **lifepool** documents must be viewed in the presence of an appointed member of the **lifepool** data management team.
7. **lifepool** participants are assigned a unique study identifier number. This will not be the same as any unique identifier assigned by a government agency (or it's agent or contractor).
8. The use of a unique study identifier means that each **lifepool** participant remains anonymous to all researchers accessing the resource. Only a small number of **lifepool** staff will have access to their identified information.
9. Any transfer of **lifepool** participant information outside of Victoria will be approved only if the recipient protects privacy under standards similar to Victoria's Information Privacy Principles and no transfer will take place unless the recipient has signed a Material Transfer Agreement.
10. Sensitive information about a participant, like their racial or ethnic origin, will only be collected from a participant with her consent.

Members of the **lifepool** Data Management Team agree to always treat **lifepool** participants courteously, and handle their personal information as described under the **lifepool** Privacy and Confidentiality Guidelines.

All Researcher queries will be dealt with professionally and in a timely manner.

Digitising of mammogram x-rays, scanning of questionnaires, consent documents and other relevant documents for storage, both in a file archive and for uploading to the relevant database, will be undertaken with care and efficiency

Read by:.....**(print name)**

Signature**Date:**.....