

1. Why is lifepool writing to you again?

Some time ago, you joined the **lifepool** project. When signing the consent form, you ticked the 'yes' box when we asked if you wished to be contacted in the future regarding possible blood donation or participation in a specific research project. You might remember that it is always your choice whether to continue being part of **lifepool**; you can opt out or change the way your information is used by **lifepool** at anytime. If you have changed your mind about future contact, just let us know by telephone or email (the details are listed in section 9 of this form) and we will record your wishes in our database.

We have written to a large group of **lifepool** participants and have included women living with breast cancer and women who do not have breast cancer

2. What do we ask of you?

We would like to ask you to donate a blood sample to be used in future research. Blood can be used for a wide range of studies including genetic research. Genetic research involves the study of genetic material (DNA). A small blood sample is the best way for **lifepool** to gather DNA for research projects, but if you are unable to donate blood, and still want to provide a sample of your DNA, we can send you a saliva kit (details in section 5)

3. What will we use your sample for?

The genetic research projects which will use DNA samples from **lifepool** will be studying genes which could be involved in development of breast cancer and genes which may have an effect on the risk of breast cancer. It is possible that future research will look at genes involved in other diseases affecting womens' health.

4. Some important facts you should know

There is a very small chance that genetic research using your DNA sample will yield information of direct importance to your health. If there is any research information thought to be of relevance to your health the Peter MacCallum Cancer Centre Human Research Ethics Committee will review advice from an expert panel and, if appropriate, contact you so that you can decide if you want to learn more about that information.

What are the benefits of finding out more about your individual research results?

If you decide you want to find out more about your individual research results, we will make clinical and counselling professionals available to explain your individual research results to you, at no cost to you.

Information about research results, such as your risk of developing breast cancer or some other health condition, could be of benefit to your health and allow you to have more frequent screening

Other implications of agreeing to provide a blood or saliva sample

Some insurance companies consider that a person's involvement in genetic testing is relevant to the insurer's decision whether to accept an application by that person for a policy and, if so, on what terms. Some insurance companies may ask specific questions about your involvement in genetic testing. If you agree to provide a blood or saliva sample you may need to disclose this fact to an insurer when making application for new insurance or to vary or renew existing insurance.

In the unlikely event that we write to you inviting you to hear more about your individual research results, simply receiving such a letter will have no impact on any insurance. But if you choose to find out more about that health information, when applying for a new insurance policy of the types listed above, or when making changes to an existing policy, you may need to inform your insurance company.

Any results or information from research studies associated with **lifepool** will not affect your health or medical insurance or certain group life insurance available through superannuation. It will also not affect certain other insurance policies that you already hold (unless you seek to vary or renew those policies).

Advice will be available to you to help you understand the health information and to understand the impact this information may have on your insurance.

5. What is involved in donating blood or saliva?

A sample of up to 20 ml (equal to 4 teaspoons) of blood is requested, and you can have this sample taken by skilled *Melbourne Pathology* staff at any centre at a time convenient for you. You just need to take the enclosed request slip with you to a *Melbourne Pathology* collection centre and they will do the rest. A list of their locations is provided.

If you are not able to give blood, but would still like to provide a DNA sample, please phone **lifepool** (details in Section 9) and we will send you a saliva collection kit in the mail. You just need to follow the simple instructions which basically involve cleaning your teeth, waiting for 30 minutes then spitting some saliva into the tube supplied. We include a reply paid pack in which to post the kit back to **lifepool**.

6. How will I be kept informed?

We will keep you informed about the general progress of the **lifepool** Project and the kind of research using **lifepool** resources by sending you a Newsletter. You can contact **lifepool** (details in Section 9) at any time if you do not wish to receive this Newsletter. As described in section 4, we will only contact you directly about research results if the Peter Mac Ethics Committee experts agree that research information is of direct relevance to your health.

7. How do Researchers access information and/or samples?

The information and samples you may choose to provide will be used by researchers from a range of institutions such as Universities, Medical Research Institutes and commercial research groups such as Pharmaceutical companies. For a researcher to gain access to samples for genetic research, they must have approval for their project from a Human Research Ethics Committee and their project must also be approved by the NBCF Access Committee.

8. Where will samples be stored and what happens if I change my mind?

Samples of DNA will be stored at the Peter MacCallum Cancer Centre. A back up of the samples may be stored at the University of Melbourne.

You are free to withdraw your consent to take part in the **lifepool** Project at any time. If you would like to stop or change the way you are currently participating, please contact **lifepool**.

9. Who can I contact if I have questions?

If you would like any further information about donating blood or saliva to the **lifepool** Project or you have questions, please contact the Manager, Lisa Devereux on **9656 1096 or 1800198 082 or lifepool@petermac.org** If you have a complaint, or would like to speak to someone who is not involved in The **lifepool** Project, you can contact The Ethics Co-ordinator at **Peter MacCallum Cancer Centre on 9656 3771**

Consent to donate blood or saliva to the lifepool Project

I(please print your name)

of (address).....

.....

Date of Birth.....

- have read the Stage 2 Participant Information Form, understand the consequences of donating a sample of blood or saliva to The **lifepool** Project and have had the opportunity to ask questions. Any questions I had have been answered satisfactorily

Participant's

Signature.....Date.....

Please keep pages 1&2 for your records. The Consent Form on page 3 should be signed & returned in the Reply Paid envelope supplied.

Original Consent Document
Please return to lifepool using the Reply Paid envelope supplied

Consent to donate blood or saliva to the lifepool Project

I *(please print your name)*

of (address).....

.....

Date of Birth.....

- I have read the Stage 2 Participant Information Form, understand the consequences of donating a sample of blood or saliva to the lifepool Project and have had the opportunity to ask questions. Any questions I had have been answered satisfactorily

Participant's
Signature..... **Date**.....

Original Consent Document

For Project Use Only
Participant ID number: _____
Database Logged: (date) ____ / ____ / ____