



Laboratory & Community Genetics

Northern Sydney Health
Consent Form to Participate in a Research Project

I, _____
(name of participant)
of _____
(street) (suburb/town) (state & postcode)
have been invited to participate in a research project entitled:

Ironman project: Optimal community screening for haemochromatosis

In relation to this project I have read the Patient Information Sheet and have been informed of the following points:

1. Approval has been given by the Human Research Ethics Committee (HREC) of Northern Sydney Health.
2. The aim of the project is to evaluate different strategies to optimise population screening, diagnosis and management of haemochromatosis, an inheritable condition of iron overload, whereby serious consequences of disease are preventable by early diagnosis and management.
3. The results obtained from the study may reveal information that is of potential importance to my future health, and may or may not be of direct benefit to my medical management.
4. The procedure will involve collection of 5mL venous blood for laboratory investigations of my iron status. If initial investigations are suggestive of iron overload, a repeat 10mL blood collection would be required for genetic test confirmation.
5. There are some possible adverse effects or risks related to this project which include:
 - i. Discomfort, swelling and bruising at the needle puncture site.
 - ii. Potential discrimination by any life-insurance companies that may require disclosure of abnormal genetic test results.
(There are currently no anti-discrimination laws for results of genetic test, but these issues of discrimination are being addressed by professional and peer support genetic groups to government and insurance groups)
6. Samples of genetic material and result information will be stored confidentially at all times. Results will only be issued to me and my referring doctor. Results will not be issued to other family members without my permission. My results may generate information that may be relevant to the health of other family members. I will then be consulted and my permission sought to approach relevant family members.

Date: _____ Witness: _____
(Please print name)

Signature: _____ Signature: _____
(of participant/volunteer) (of witness)

Investigator's Signature: _____

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- 7. No genetic material or information will be released without my consent for use in any other way except for the purposes of HREC approved research, unless required by law.
- 8. Should I wish to further discuss issues relevant to genetic testing, I am aware that I may contact the Genetic Counselling Service, Royal North Shore Hospital on 9926 6478 or the PaLMS Laboratory & Community Genetics on 9926 7166.
- 9. Should I develop a problem which I suspect may have resulted from my involvement in this project, I am aware that I may contact -
Dr Lisa Koe on 9926 7453 / 41503 (phone and page numbers)
- 10. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the Patient Representative who is an independent person within the Hospital on 9926 7612.
- 11. I am free to refuse to take part in this project or withdraw from it at any time without giving any reason(s). Withdrawal will not affect medical care provided to me.
- 12. Participation in this project will not result in any extra medical and hospital costs to me.
- 13. If the results of this study are published, all information on my test results and clinical background will be completely de-identified and my identity will not be revealed.
- 14. I am aware that genetic testing has the potential to detect non-paternity or non-maternity.

I am of ethnic Caucasian background

YES

NO

I have/have not symptoms related to haemochromatosis (ie. diabetes, heart muscle weakness, arthritis, liver disease)

HAVE

HAVE NOT

I have/have not first degree relative(s) diagnosed with haemochromatosis

HAVE

HAVE NOT

Date: _____

Witness: _____
(Please print name)

Signature: _____
(of participant/volunteer)

Signature: _____
(of witness)

Investigator's Signature: _____



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After considering all these points, I accept the invitation to participate in this project.
I also state that I have/have not participated in any other research project in the past 3 months.
If I have, the details are as follows: _____

Dr _____ on _____
(phone and page numbers)

Date: _____ Witness: _____
(Please print name)

Signature: _____ Signature: _____
(of participant/volunteer) (of witness)

Investigator's Signature: _____