



Participant consent form

I confirm I have been given a participant information brochure.

I understand and agree to the following:

- I am aged 18 years or older.
- I have read and understood the Participant Information Brochure [AHB_PIB_V1.2_24March2022].
- I have been able to ask any questions I have and they have been answered to my satisfaction.
- I know it is my choice to donate samples or not and am making that choice freely.
- I know my decision to participate or not will not affect my healthcare, medical treatment or access to government services, now or in the future.
- I know that I am not likely to benefit directly from being involved in the biobank.
- I understand I can choose to stop taking part at any time.
- I know that my samples and information could be held indefinitely.
- I know that while I can ask for my samples to be destroyed at any time it may not be possible to remove information already obtained from analysing my samples when the work has already been published.
- I know that my samples and results from research done on my samples may be provided to researchers not involved with the biobank for use in health and medical research projects in the future and I won't get to choose which ones they are used in.
- I know that the results of research done on my samples could be linked to health information and information that is already held by the Australian Bureau of Statistics (ABS) or State and Commonwealth governments.
- I know that the biobank will decide who my samples are released to.
- I know that I will receive \$75 to cover the costs associated with having my samples collected.
- I know that I won't get any financial benefit if a commercial researcher makes money from products that might come of the research that is conducted on my samples.
- I know that I won't be told directly what research projects my samples are used for, and that I won't receive my own results of any research done on my samples.
- I know that it is possible that researchers could discover things that have serious and important health consequences for me or my family and that I will be told about these, if I choose, by this being told to my doctor.
- I know that my samples and information will not include my name, contact details or other information that identifies me when they are sent to researchers, but the biobank will keep these details about me separately so they can contact me.
- I know that while my samples and personal information will be protected and stored securely there is a very small possibility that researchers may be able to identify me.



I consent to:

- Donate samples (~20ml of blood and ~20ml of urine) to the Australian Health Biobank to be stored indefinitely in a secure facility.
- Have my sample, and the results from research done on my sample, made available to approved researchers for future health and medical research.
- Have the results from research done on my sample linked to existing health and general information about me (like my job, age or gender) that is held by the ABS or State and Commonwealth governments in a way that doesn't identify who I am.
- **The Australian Health Biobank Team contacting me in the future to provide updates or ask for participation in new research projects** Yes No (PLEASE SELECT WHICH IS APPLICABLE)

Participant name: (PLEASE PRINT)

Participant signature:

Date:

Optional consent for genomic research

I consent to the use of my samples for future unspecified genomic research projects:

Yes No (PLEASE SELECT WHICH IS APPLICABLE)

If I do consent, I understand and agree to the following:

- I know that it is my choice to allow genomic tests to be undertaken on my samples, and if I choose not to, I can still be involved in all other projects in the biobank.
- I know that my genomic information will be securely stored in a dedicated database managed by the Australian Health Biobank and will not include my name or contact details or other information that identifies me.
- I know that it is very unlikely that I can be identified from genomic research on my samples, but there is a very small chance that this could happen.
- I know that I can choose to stop sharing my samples and/or information for genomic research at any time, and that this will not affect my involvement in other research in the biobank.
- I know that my genomic information may be deposited in special international databases, so that international researchers can share this information to help support health and medical research. I understand that this information will not include any details that could identify me.

I confirm that I understand the requirements of participation in the Australian Health Biobank Genomic research and that I have willingly provided consent to participate. I understand that I am free to change whether or not I wish my samples to be used for future genomic research.

Participant name: (PLEASE PRINT)

Participant signature:

Date:



Optional consent for return of serious findings from genomic research

The Australian Health Biobank may learn about a serious finding that has health implications for you or your family due to genomic research projects using your samples. It is up to you to decide whether you would like to be told about findings like these and whether you would like your family to be told if you're not contactable.

I **wish** to be notified if research using my samples reveals information that has significant implications for me or my family.

Yes **No** (PLEASE SELECT WHICH IS APPLICABLE)

In the event that I am uncontactable:

I **wish** for my family or nominated person (as listed below) to be contacted if research using my biological samples reveals information that has significant implications for me or my family.

Yes **No** (PLEASE SELECT WHICH IS APPLICABLE)

I understand that if I do wish that I or my nominee to be notified about a serious finding, this will be done with appropriate counselling and support provided by experienced health professionals, in line with the *National Statement on Ethical Conduct in Research Involving Humans (2018)*.

I understand that in rare cases these findings may affect insurance that I or my genetic relatives may apply for in the future.

I understand that the Australian Health Biobank will need to contact my doctor in the event of a serious finding.

I need to tell the biobank if these details change.

Doctor name and/
or Medical Clinic:

Doctor address:

Suburb/City:

State:

Postcode:

I confirm that I provide consent for the Australian Health Biobank to contact me in the event of a serious finding being made that could affect the health of me or my family and understand the potential implications.

I understand that I am free to change whether or not I wish to be contacted regarding any serious genomic findings at any time.

Participant name: (PLEASE PRINT)

Participant signature:

Date:

Optional nomination of an alternative contact

You can nominate a person or people for the AHB to contact if you die, are medically unable to make decisions or we can't get in touch with you directly. The nominated person/people should be someone that you trust and may be asked to provide your new contact details (if you have moved or have a number phone number/email), make decisions about the use or destruction of your samples, or (if you have provided consent) be informed of serious findings that could impact you or your family.

If you choose to nominate an alternative contact person or people, then you should talk to them about this to make sure they understand that they may be contacted and under what circumstances, and that they are happy to act in this role.

If you do not provide an alternate contact and we are not able to get in touch with you, then what you have consented to previously will continue to apply until such time as you either change it or provide us with an alternate contact person or people.

I understand that I will need to provide my alternative contacts with information about the study so that they understand what is being asked of them and obtain their consent for CSIRO to collect their name, address, email and phone number so that CSIRO may contact them and ask them to provide my new contact details, make decisions about the use or destruction of my samples, or (if I have consented) be informed of serious findings that could impact my family.

I wish for my family or nominated person/s listed below to be contacted if I die, am unable to make decisions or am otherwise uncontactable:

Yes No (PLEASE SELECT WHICH IS APPLICABLE)

If you wish to nominate a person/s, please add their contact details below:

First nominee

Full name:

Relationship to me:

Address:

Suburb/City:

State: Postcode:

Phone:

Email:

Second Nominee (OPTIONAL)

Full name:

Relationship to me:

Address:

Suburb/City:

State: Postcode:

Phone:

Email:



Participant confirmation

I confirm that I understand the requirements of participation in the Australian Health Biobank and that I have willingly provided consent to participate and confirm that I have completed all relevant sections of the Consent Form. I understand that I can choose to discuss my participation in the Biobank with my family or friends, and that I can choose not to participate. I also understand that I can withdraw from any aspect at any time.

Participant name: (PLEASE PRINT)

Address:

Suburb/City:

State:

Postcode:

Date of birth:

Gender:

Phone:

Email:

Participant signature:

Date:

Translator information (if applicable)

All translators engaged either in person or via telephone for the translation of the participant information brochure, consent form and all information presented regarding the Australian Health Biobank must hold credentials issued by the National Accreditation Authority for Translators and Interpreters (NAATI) for the consent to be valid.

Date:

I, [redacted] [name of investigator/designee] confirm that the translator engaged for the translation of the participant information brochure, consent form and all information presented regarding the Australian Health Biobank has provided me with their National Accreditation Authority for Translators and Interpreters (NAATI) number issued by the NAATI.