



# Participant information brochure

You are being given this information brochure because you are being invited to participate in the Australian Health Biobank.

The information is important to help you decide whether to donate a sample to the Australian Health Biobank for use in future health and medical research. Read it carefully and ask as many questions as you like.

If you want to, you can ask questions about the biobank of:

- the person who gave you this information brochure and is asking for your consent,
- your doctor or other healthcare professional,
- your family and friends.

You can also find more detail about some of the topics covered in this information brochure on the **Australian Health Biobank website [csiro.au/biobank](https://www.csiro.au/biobank)**.

You are being invited to give your consent to:

- Donate blood and urine samples to the Australian Health Biobank to be stored indefinitely.
- Have your samples and the results from research done on your samples, made available to approved researchers for future health and medical research.
- Have the results from the research done on your samples linked to existing health and general information about you (like your job, age or gender) that is held by the Australian Bureau of Statistics (ABS) or State and Commonwealth Governments.

## What is the Australian Health Biobank?

The Australian Health Biobank is being set up to provide a national collection of biological samples from the Australian population. This will provide a unique resource for researchers in the future to undertake a wide range of research projects to improve the health and wellbeing of Australians. The Australian Health Biobank will help make this research easier by making a collection of samples available to researchers that represent the Australian community.

Samples for the Australian Health Biobank will be collected from 2022 to the middle of 2024 from participants of the National Health Measures Survey who agree to also donate samples to the biobank.

From the middle of 2024 researchers will be able to apply to the Australian Health Biobank for access to samples (or information from research undertaken on your samples) for their projects. They will also be able to apply to link the results generated from samples in the biobank to other existing health and general information.

All research projects conducted using samples or information from the biobank will need to have the potential to make a significant contribution to health and medical research and benefit the health and wellbeing of Australians.

## Who is funding the Australian Health Biobank?

The Australian Health Biobank is being funded by the Australian Department of Health who have contracted the Commonwealth Scientific and Industrial Research Organisation (CSIRO) to act as the Australian Health Biobank Custodian.

The CSIRO will oversee that your samples, personal information and any results from your samples are stored securely. They are also responsible for making your samples (and information that is generated from these samples in the future) accessible to researchers.

The CSIRO will be the point of contact both for people who donate to the biobank and for the researchers who use the biobank.



## How to donate to the Australian Health Biobank

If you decide to contribute to the biobank, you will be asked to attend a second appointment at a Sonic Pathology Australia collection centre to donate blood (approximately 20 ml or 1 tablespoon) and urine (approximately 20 ml or 4 teaspoons) to the biobank.

This can be at the same collection centre as the one you attend to provide blood and urine samples for the National Health Measures Survey, or a different collection centre if this is more convenient. For a list of the closest collection centres please:

**Visit: [soniccommercialpath.com.au/our-locations](https://soniccommercialpath.com.au/our-locations)**

**Call Sonic: 1800 577 500**

**Otherwise speak to your interviewer or call the ABS on 1800 482 517.**

You will be given a separate referral form for the biobank, which you will need to take to the collection centre when you get your samples collected. There is no cost to you for this and you will receive a \$75 gift card to help cover any costs, such as travel expenses or childcare, for visiting a collection centre. This will occur automatically once the ABS receives notification that you have attended your second appointment at a collection centre. You should receive this within 3 weeks from when you provide samples.

If you find it difficult getting to a collection centre, please let the interviewer know or call 1800 482 517 to discuss other options such as a home visit. *Note: A gift card is not provided if you receive a home visit.*

If you decide to provide samples to the biobank, we will also collect some personal information (like your name and contact details) so we can keep in touch with you.

## It is your choice to donate or not

Choosing to donate your samples for health and medical research is voluntary. This means you don't have to do it if you don't want to and there won't be any consequences for you if you choose not to. You can talk to your doctor, family or friends before you decide, but remember the decision to donate or not is yours.

Your decision of whether you donate samples to the Australian biobank or not will not affect your healthcare, medical treatment, or other services you receive from the government, now or in the future.

## You are not likely to benefit directly

You are not likely to get any direct benefits from donating to the biobank. However, the results of research using your samples could help to improve the health and wellbeing of Australians in the future.

## Your samples could be held indefinitely

Researchers are continually making new discoveries, and new diseases are always emerging. To make sure the Australian Health Biobank can support health and medical research long into the future we could keep your samples in the biobank indefinitely, or until you choose to stop taking part.

## You can choose to stop taking part at any time

If you choose to donate a sample, but change your mind later, that is ok. The decision will not affect your medical treatment or healthcare in any way.

If you choose to stop taking part, the samples you donated will be removed from the biobank and safely destroyed and if any of your samples have already been given to a researcher, they will also be asked to destroy them.

If research has already been carried out on your samples, you can also ask that this information is deleted. You should be aware that it isn't possible to remove information from your samples from studies that have already been published.

If you choose to stop taking part, you can contact the Australian Health Biobank using the details below or visit [csiro.au/biobank](https://csiro.au/biobank). Once you withdraw, we won't contact you again and will remove your information from our database.

## How your samples could be used in research

From around the middle of 2024 (when all samples for the biobank are collected), approved researchers can request access to biobank samples and related data.

Your sample and results of research done on these samples could be used for a range of different health or medical research projects, now and in the future. Some examples could include:

- Research to help us understand why some people are more likely to get to certain diseases than others.
- Research that identifies how different people react to the same treatment – which could help make these treatments work better.
- Research to look at levels of nutrients or toxins in the Australian population.

Any results from research done on your samples will also be returned to the Australian Health Biobank, so that this information can be made available to other researchers for new research projects without using more of your samples.

To be approved by the biobank to access your samples and information related to them, researchers will need to be able to demonstrate that their research contributes to the aim of the Australian Health Biobank, which is to improve the health and wellbeing of Australians. Researchers will not have access to any information that could identify you (like your name and contact details).

It's important for you to know that you won't get to choose how your samples and information are used after you donate them.

## Your samples might be used for genomic research, but only if you agree

Genes are the basic “instruction book” for the cells that make up our bodies. All genes are made of DNA. The complete set of DNA in your body, including all its genes, is called your genome. Although our DNA is very similar to each other, your DNA is entirely unique. Genomic technology allows researchers to test many genes at once (genomic testing).

Being able to test a person’s DNA or genomic information helps scientists understand how to predict diseases and potentially treat them. Because there are similarities in the DNA or genomic information of different people, the results of testing one person can help understand how to treat a disease in another person.

Because your genomic information is unique to you it could also be used to identify you and could provide information about your health or risk of getting specific disease in the future. Researchers who want to access your genomic information must agree not to attempt to identify who you are, and to handle your genomic information carefully to ensure your privacy is protected. We will also ask you if you want to learn about any information we learn while looking at your DNA about risks to your health.

When researchers share the results of their projects that involve genomic information, they often need to share some of the genomic information they used so that other researchers can learn from their research. Because genomic information can identify who you are if it is combined with other genomic information (like data from genomic testing companies), researchers must agree to be careful about how they share this information, so it doesn’t let other people identify you. Genomic technology keeps changing quickly however, so while we will do this, we can’t guarantee that genomic information that is shared about you won’t allow people to work out who you are in the future.

You can choose whether you want to allow genomic research to be done on your samples when you complete the Australian Health Biobank consent form. Whether you decide to agree to genomic research being done on your samples or not, will not affect the use of your samples in other types of research. You can also change your mind about agreeing to let your samples be used in genomic research at any time by contacting us or visiting [csiro.au/biobank](http://csiro.au/biobank).

*For more detailed information about genomic research, please see the FAQs section of the Australian Health Biobank website.*



## Results of research on your samples could be linked with your health information and general information that describes who you are

As part of being involved in the biobank, you consent to having the data from research done on your samples linked to existing health and general information about you (like your job, age or gender) that is held by the Australian Bureau of Statistics (ABS) or State and Commonwealth Governments.

Being able to link the information from research on samples from the biobank to these other types of information is important to help researchers better understand the things that could change the risks of disease and allow them to better prevent and treat it.

The type of information that they could link to could include:

- information collected as part of the National Health Survey and the National Nutrition and Physical Activity Survey,
- the times you go to see a doctor (based on Medicare claims information),
- the prescription medicines you get from a pharmacy (based on Pharmaceutical Benefits Scheme claims),
- other information that affects health, such as your education, employment and lifestyle.

Before information from research done on your samples is combined with any other information the research will need to be approved by the biobank and by the ABS, who follow strict protocols to protect your privacy and keep the information secure. **The ABS doesn’t keep any personal information (like your name and address) with their data, so it can’t be linked to information that could identify you.** If a linkage project is approved, the linking of the information will be done by the ABS on a secure platform and the results deleted after they have been provided to the researcher who requested them.

*For more detailed information about data linkage, please see the FAQs section of the Australian Health Biobank website.*

## Commercial researchers could request access to your samples in the future

The Australian Health Biobank is being set up as a national resource to benefit the health and wellbeing of Australians into the future and will be a not-for-profit activity.

It’s possible that research done on your samples could lead to discoveries that lead to the development of a new test or product. It’s also possible that the researchers or company that makes this discovery could make money from it.

If this happens, this money will be paid to the company or researchers who made the discovery and will enable them to continue to do more research. Neither you nor the biobank will receive any financial benefit if this happens.

*For more detailed information please see the FAQs section of the Australian Health Biobank website.*

## Where your samples and information will be stored

Your samples will be stored in a secure biobanking facility (further details are available at [csiro.au/biobank](https://csiro.au/biobank)). The samples will be kept in locked freezers and will only be accessible to authorised individuals.

Your personal information, details about your samples and results of research on your samples will be stored on secure, password protected servers by the CSIRO.

## How researchers will access your samples and information

Before the biobank allows researchers to use your samples or information, their research project will need to be approved by an ethics committee (to make sure that the research respects and protects you and the other people who have donated samples). The research must also be compliant with all relevant legal or other requirements. The biobank will only approve the use of your samples and information for research that is high quality and has a high chance of improving the health and wellbeing of Australians.

Once a research project is approved, the biobank will organise for your samples and/or information from previous research on your samples to be sent to the researchers to do the project. Once the research is finished, the researchers will need to destroy any remaining samples or send them back to the biobank. They will also need to give the biobank a copy of any information from research on your samples.

## Your sample and information from your sample can only be used by approved research projects in Australia

Your samples and information held by the biobank about research on your samples will not be sent overseas, and all analyses on your samples will be carried out in Australia. This is important to make sure that the use of your samples and information is covered by Australian laws and privacy regulations.

## You won't get individual results from research projects, but you can find out what projects your samples contributed to

In most cases, you won't find out your own results from any research that are done on your samples. You will, however, be able to find out about whether your samples have been used in research and the type of research projects they have been used for.

To let you do this, we will give you a special link and a password that is unique to you, that you can use on the Australian Health Biobank website. This link and password will be sent to you either by email or post after your biobank samples have been collected.

Information on all research projects that are done using samples or information from the biobank and the results of these projects will be also listed on the Australian Health Biobank website ([csiro.au/biobank](https://csiro.au/biobank)) so you can see what the research that used your samples discovered.

## If you agree for your samples to be used in genomic research, researchers could find things that have serious and important health consequences for you or your family

When testing your sample, there is a very small chance that researchers may find out that you or your family members might be at risk of a serious health condition. For example, they may discover you have a gene that puts you at risk for sudden heart attack, a type of cancer or another life-threatening condition that can be treated. This gene might be something you share with your genetic relatives, such as your parents, siblings or children.

In case this happens, we are asking you to nominate a doctor who we can contact if something serious is discovered.

If something potentially serious is found by a researcher, it will first be reviewed by clinical experts. If these experts confirm the researcher's finding, then they will inform the doctor you have nominated. Your doctor will then contact you to explain that something serious has been discovered, explain what the finding is and refer you to a medical expert or genetic counsellor who can assist you with the next steps.

They will only contact you if the finding is significant and confirmed and if there is something that can be done to help you or your family to stay well (like a specific treatment or lifestyle change). General or non-specific health information generated in research projects – such as evidence of a risk of high cholesterol or a gene that only gives you a slightly increased risk of a common medical condition – will not be returned to you.

If you're *not* contacted about a finding, it does not mean you don't have any health issues. Researchers do not perform general testing on your sample, so it is important to continue your regular health check-ups with your family doctor and other health professionals.

You can decide *not* to be contacted about serious findings if you wish.

In rare cases, taking part in health and medical research might affect health or life insurance cover for you and your blood relatives. For example, if you have a serious and life-threatening genetic condition that you share with your family, it could affect insurance that you or they apply for in the future (for example life insurance or income protection). It's important for you to consider this risk before deciding if you want to be contacted about any serious findings.

If something happens in the future which means you can't make decisions for yourself, you can let us know now (on your consent form) if you want your family to be informed in your place if we find a serious finding related to your samples.

*For more detailed information on serious findings, please see the FAQs on the Australian Health Biobank website.*

## Your information and samples will be protected

Your samples will be labelled with an Australian Health Biobank reference number before they are stored in the biobank. There will be no personal identifying information written on your samples.

Your personal information (like your name and contact details) is stored according to strict security and privacy protocols and in line with legal and ethical requirements. This information will be stored in a separate database to the database where we store the results of research done on your samples, including any genomic information.

Researchers who access your samples or results from your samples will never be given any information that identifies you, so they won't be able to tell who you are.

Only individuals who are authorised by the Australian Health Biobank will be able to access your samples or information. This includes staff in the biobank facility and CSIRO employees who manage the project or databases. All these people will have to complete regular police checks and will be bound by strict privacy and confidentiality protocols.

## What are the risks?

While we will do everything we can to protect your privacy and confidentiality, there is a small risk that breaches could happen.

In rare cases, researchers might identify you from your information. If this happens, researchers are required by law to maintain your privacy and report any breaches to us and to the relevant ethics committee/privacy officers. If a breach of privacy happens, it will be dealt with in line with privacy laws and guidelines.

In very rare cases, we may have a legal obligation to make your information available to third parties who are not approved researchers. For example, in the case of a new infectious disease that could affect other people both you and other parties would be informed, or we may have to provide information to the courts because of a legal process.

## There are times we will need to contact you

Once you've had your samples for the biobank collected, you will be given the option to receive regular newsletters. These newsletters will only be sent to participants in the biobank and will include updates on the progress of the biobank. You can choose to receive newsletters by email or by post and you can opt in or out of receiving them at any time, either via the Australian Health Biobank website or by getting in touch with us by phone, email or by post.

It is also possible in the future that some researchers will want to do research projects where they need to collect some additional information (for example, extra samples or a new survey). If this happens, a person from the Australian Health Biobank may contact you on behalf of a researcher to ask if you want to participate in a project like this. If you are contacted in the future, you can decide if you want to take part without affecting your participation in the biobank. You can also decide not to be contacted about this type of research if you would prefer not to.

As indicated above, your doctor may contact you if something is discovered that has serious health implications for you or your family. If we cannot contact your nominated doctor we may also contact you to find out the details of another one.

Finally, we may need to contact you from time to time to let you know about changes to the biobank that may impact on your decision to continue to take part or may change how your samples and information are used. Because of this, it's important that you keep your contact details with us up to date.

You can also nominate one or two people who we can contact if we aren't able to get in touch with you in the future. You will be asked to nominate these people on your biobank consent form. You should let this person/people know that you have nominated them as a contact and confirm they are happy to act in this role for you. You can change these people at any time by contacting us or via the Australian Health Biobank website.

If you don't 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.



## You can contact us at any time

You can contact the Australian Health Biobank at any time. You can do this either via the Australian Health Biobank website, or contacting us by phone, email or by post. **Details at the bottom of the page.**

As a biobank participant, you will be given a password that you can use to access a private page on our website that only you can get to. This page will provide information on your samples and how they have been used. You will also be able to manage your consent status, opt in or out of receiving newsletters or information about additional research, and update your contact information.

The forms for changing your consent status, updating your contact details, or changing your nominated contacts will also be available on the Australian Biobank website. You can either complete these forms online or download them and send back to us by email or post if you prefer.

## If you have a complaint or concerns

If you have any concerns, feedback or complaints that you don't want to discuss with the biobank, then please contact the Human Research Ethics Committee that approved the project. This committee is independent from the biobank and helps ensure it has the best procedures in place to protect your samples and information, and that these are always followed.

### CSIRO Health and Medical Human Research Ethics Committee

(07) 3833 5693  
chmhrec@csiro.au

### Privacy

For further information on how CSIRO handles your personal information and our complaints process please read our privacy policy available on our website at <https://www.csiro.au/en/about/policies/privacy> or contact us at [privacy@csiro.au](mailto:privacy@csiro.au).

## What happens next?

If you agree to donate samples for the Australian Health Biobank:

- Sign the biobank consent form and leave it with the ABS interviewer.
- Provide blood and urine samples for the National Health Measures survey at any Sonic Pathology Australia collection Centre (*Visit 1, See National Health Measures Survey Information Brochure*).
- Donate additional blood and urine samples for the Australian Health Biobank at any Sonic Pathology Australia collection centre (*Visit 2*), as soon after your first visit as you can.
- You will need to take your biobank referral form to the collection centre.
- You will not need to fast for this additional collection of blood and urine for the biobank.
- Provide your details so that we can keep in touch with you if you want us to.
- We will send you a copy of your signed consent form for your records.

*Please keep a copy of this information brochure, along with your signed consent form.*



### You can contact us at:

Australian Health Biobank  
PO Box 10041  
Adelaide BC SA 5000

### CSIRO Enquiries

1300 363 400  
[biobank@csiro.au](mailto:biobank@csiro.au)  
[csiro.au/biobank](http://csiro.au/biobank)