









Australian Haemochromatosis Registry Participant Information

This information is important to help you decide whether to participate in the Australian Haemochromatosis Registry. Please read it carefully and ask your family and friends, your doctor and others involved in your health for advice. You can contact Haemochromatosis Australia on 1300 019 028 if you have any questions.

You can also find more detail about some of the topics covered in this information brochure on the Haemochromatosis Australia's website www.ha.org.au.

What is the Australian Haemochromatosis Registry?

The Australian Haemochromatosis Registry (AHR) is a national collection of de-identified data from individuals in Australia with haemochromatosis. It is a collaborative project between Haemochromatosis Australia, QIMR Berghofer Medical Research Institute, Edith Cowan University and the Queensland University of Technology, with support from Australian Red Cross Lifeblood and Hunter Medical Research Institute.

Haemochromatosis Australia is the custodian of the Australian Haemochromatosis Registry and is responsible for the safe and secure storage of your personal information. Haemochromatosis Australia is the point of contact for participating patients and registers seeking access to information for research.



Why is it important?

The Australian Haemochromatosis Registry enables research into the role of iron in a number of related chronic health conditions including liver disease, arthritis, diabetes and heart conditions. It will also support opportunities for future research into the impact of iron on the brain and facilitate research into new treatments for all the conditions mentioned above. All research projects conducted using information from the Australian Haemochromatosis Registry will ultimately benefit the health of people with haemochromatosis.

Who is funding the Australian Haemochromatosis Registry?



The Australian Government Department of Health and Aged Care has provided funding for the Australian Haemochromatosis Registry project.

How do I join Australian Haemochromatosis Registry?

To join the Australian Haemochromatosis Registry go to www.registry.haemochromatosis.org.au

How can I participate?

There are two options for participation in the Australian Haemochromatosis Registry. You may choose to participate in one or both of the following options:

- online questionnaires
- linkage to health and lifestyle data held by government agencies including but not limited to your *'My Health Record'*, pathology test results, scan and X-ray reports, gene test results, prescription medicines dispensed.

Online questionnaires will ask you for information about your diagnosis and treatment. Data linkage will link information about you held by Commonwealth and State health agencies, health care providers, Services Australia and the Australian Institute of Health and Welfare. This may include your digital or electronic medical records (EMR) data from hospitals, day clinics and pathology services, as well as data from your *'My Health Record'*.



Who benefits from the Australian Haemochromatosis Registry?

You are not likely to get any direct benefits from participating in the Australian Haemochromatosis Registry. However, the results of research using your information could help to improve the health and wellbeing of Australians in the future. To make sure the Australian Haemochromatosis Registry can support health and medical research long into the future, we may retain your information indefinitely, or until you choose to stop taking part. We will also send you an email every year asking you to update any details that have changed. In this email, we may also remind you to ask your doctor for an annual iron studies test.

Although you will not directly receive results from research projects, you can find out what research studies are using the Australian Haemochromatosis Registry. Information on all research projects using data from the Australian Haemochromatosis Registry will be listed on the Australian Haemochromatosis Registry website <http://registry.haemochromatosis.org.au>

It is important for you to know that you will not get to choose how the information you provide is used. As part of being involved in the AHR, you have the option to consent to having relevant data held by the agencies linked to the research. If consent is provided, the types of information that could be linked to your AHR record include:

- information collected in national health, nutrition and physical activity surveys
- 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.

What is the approval process for researchers wanting access to my information?

Researchers submit their research proposal to the Australian Haemochromatosis Registry Research Approval Committee for review and assessment. Researchers will need to demonstrate that their research contributes to the aim of the Australian Haemochromatosis Registry, which is to improve the health and wellbeing of people with haemochromatosis.

The Australian Haemochromatosis Registry will only approve the use of your information for research that is high quality and has a high chance of improving the health and wellbeing of people with haemochromatosis.

Before researchers are allowed access to information in the Australian Haemochromatosis Registry, they must gain ethics approval for the research project. Their research must be compliant with all relevant legal or other requirements. Researchers will not have access to any information that could identify you (like your name and contact details).



How often will you collect my information and what happens to it?

We will collect information from you on registration and every five years after that. We will also ask you to update your contact details once a year.

The Australian Haemochromatosis Registry will be stored on secure, password protected servers by the Hunter Medical Research Institute.

Once a research project is approved, the Australian Haemochromatosis Registry will organise access to your de-identified information for the researchers for their specific study. Once the research is finished, the researchers will need to give the Australian Haemochromatosis Registry a copy of any findings from research using your information.

Your information can only be used by approved research projects in Australia; however, some of these research projects may involve international collaborations. The security of your information is covered by Australian laws and privacy regulations.

All the information and data you provide to the Australian Haemochromatosis Registry will be securely stored by the Hunter Medical Research Institute.

What are the risks to my privacy?

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.

For further information on how the Australian Haemochromatosis Registry handles your personal information and our complaints process, please read our privacy policy available on our website at <http://registry.haemochromatosis.org.au> or contact us at patientregistry@ha.org.au.

When will you contact me?

We may contact you

- to ask for clarification of information already provided
- to ask for further information and seek your consent for future research
- to update your contact details and upload pathology reports

It is possible in the future that some researchers will want to do research projects where they need to collect some additional information. If this happens, the Australian Haemochromatosis Registry may contact you on behalf of a researcher to ask if you want to participate in a project like this. Your decision on whether or not to participate in specific research projects will not affect your participation in the



Australian Haemochromatosis Registry. You can also decide not to be contacted about this type of research.

We may need to contact you from time to time to let you know about changes to the Australian Haemochromatosis Registry that may impact your decision around participation or how your information is used. Because of this, it is important that you keep your contact details with us up to date. We will send you an email every year asking you to update your contact details if anything has changed. In this email we may also remind you to ask your doctor for an annual iron studies test.

You can also nominate one or two people who we can contact if we are not able to get in touch with you in the future. 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 Haemochromatosis Registry website. 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.

What if I want to stop taking part?

If you choose to join the registry and participate in research but change your mind later, your decision will not affect your medical treatment or healthcare in any way.

You may decide that

- you do not want to be contacted for future surveys or research projects but you are happy for your data to be kept in the Registry to be used for future research, or
- you do not want to be contacted for future surveys or research projects and request that all your data be removed from the Registry and destroyed so that it cannot be used for future research.

If you choose to stop taking part in future surveys or research, your information will be removed from the registry and destroyed. However, you should be aware that it is not possible to remove information from studies that have already been published. To withdraw you can contact the Australian Haemochromatosis Registry using the details below, or visit <http://registry.haemochromatosis.org.au>. Once you withdraw, we will not contact you again.

What if I have a complaint or concerns?

If you have any concerns, feedback or complaints that you do not want to discuss with the Australian Haemochromatosis Registry, then please contact the Human Research Ethics Committee that approved the project at Human-Ethics@newcastle.edu.au citing *Protocol number: H-2024-0177*. This committee is independent from the Australian Haemochromatosis Registry and helps ensure it has the best procedures in place to protect your information and that these are always followed.



What happens next?

If you are eligible and consent to participate in the Australian Haemochromatosis Registry, we will send you a copy of your signed consent form for your records. Please keep a copy of this Participant Information document, along with your signed consent form.

When can I contact you?

You can contact the Australian Haemochromatosis Registry at any time. You can do this either via the Australian Haemochromatosis Registry website, or contacting us by phone, email or by post. See contact details at the bottom of the page. The forms for changing your consent status, updating your contact details, or changing your nominated contacts will also be available on the Australian Haemochromatosis Registry website. You can either complete these forms online or download them and send back to us by email or post if you prefer.

You can contact us at:

patientregistry@ha.org.au

Haemochromatosis Australia InfoLine: 1300 019 028

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