Welcome to the Australian Haemoglobinopathy Registry (HbR)!

What is it, why do we need it, and how can you be involved? Let's start with some background information:

The HbR was established in 2013 to help answer a number of questions important for those living with haemoglobinopathies including thalassaemia and sickle cell disease; and for those who care for and provide services for people living with an haemoglobinopathy. Registry data from an independent source like Monash University can be used by the community as well as clinicians, hospitals and governments to improve care and to plan for future needs.

Why do we need a Haemoglobinopathy Registry?

We still don't know how many people in Australia are living with haemoglobinopathies such as thalassaemia or sickle cell disease. We don't have a national picture of the health needs of people living with haemoglobinopathies and whether these needs are being met and, importantly, what can be done to improve treatments and services. With information from the HbR we can start to address these questions.

What data are collected and who has access?

The HbR collects information that is vital to providing resources for the best care of patients. It includes:

- Patient demographics including ethnic heritage
- Travel time to primary treatment centre
- Diagnoses (eg beta thalassaemia, alpha thalassaemia, sickle cell disease)
- Laboratory results
- Transfusion requirements
- Antibodies to transfused red blood cells
- Iron chelation type and dose
- Hospital admissions
- Complications of condition and treatments

Information is collected on joining the registry and then updated annually or after a significant change in treatment.

The HbR is a secure database and only authorised people can access data. These include registered clinicians at treating hospitals, who can only see their own patients' information and Monash University HbR staff.

No individual information is disclosed. We only report aggregate data that does not and cannot identify patients.

Monash University is independent; we are not influenced by government or by pharmaceutical companies. We have developed very strong data security and patient privacy processes, and data analysis is performed by HbR staff with expert clinical input.

How does the HbR work?

The HbR is a collaboration between patients, clinicians, hospitals and Monash University. Treating doctors invite patients to participate and provide them with an information brochure about the registry. Participants can the decide if they want to join the registry and can opt out of the registry at any time in the future if they change their mind.

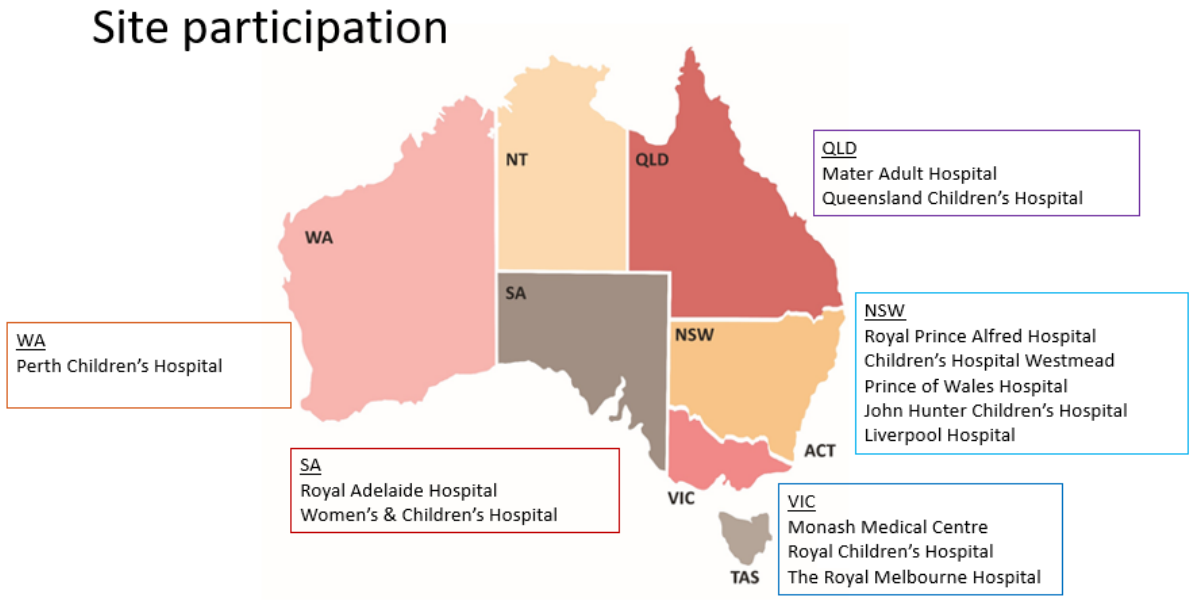
What are the aims of the HbR?

The aims are to understand how patients access care as well as the patterns and variation in care and how these affect the quality of care and outcomes for patients.

With this information we aim to:

- provide benchmarking for clinical care,
- assist with health service planning.
- provide a platform for further research including for clinical trials of new treatments

Which hospitals are participating?



What can you do to help?

Please, say yes and be included in the HbR when invited by your doctor.

Ask your doctor about the HbR:

- Is your hospital participating?
- Is your annual update completed and the information entered into the registry?

Help us:

- Find ways to support the HbR (it needs funding to continue its work!)
- Share the results

More information: hbr@monash.edu
www.monash.edu/medicine/sphpm/registries/hbr