

Haemoglobinopathy Registry

ACTRN12617000051347

Status	RECRUITING
Sponsor	Monash University
Enrollment	1,000 participants

Plain Language Summary

This registry collects information on people living with inherited blood disorders, including sickle cell disease, thalassaemia, and other haemoglobinopathies. The goal is to track how these conditions are managed and how patients do over time, so that doctors can learn what treatments work best. The information is collected through your treating doctor and stored in a secure online database.

You may be eligible if:

- You have been diagnosed with sickle cell disease, alpha-thalassaemia, beta-thalassaemia, or another haemoglobinopathy

You may NOT be eligible if:

- You have chosen to opt out of the registry

Talk to your doctor about whether this trial might be right for you.

Key Eligibility Criteria

Inclusion (1)

- Patients with a diagnosis of sickle cell disease, alpha-thalassemia, beta-thalassemia and other haemoglobinopathies.

Exclusion (1)

- patients who have chosen to opt-off the registry.

Locations (12 total)

Monash Medical Centre - Clayton campus - Clayton, NSW,QLD,SA,WA,VIC, Australia

The Royal Childrens Hospital - Parkville, NSW,QLD,SA,WA,VIC, Australia

Royal Prince Alfred Hospital - Camperdown, NSW,QLD,SA,WA,VIC, Australia

... and 9 more locations