

How long will my information be kept?

- ♥ Your name and information will stay on the Register until you finish treatment.
- ♥ You can withdraw your consent for the Register at any time by talking to your health team.



More information about RHD is available in the RHD Australia “Things you need to know” booklet available on their website: www.rhdaustralia.org.au

You can also talk with your health care team, doctor, nurse or Aboriginal health worker, or call your local public health unit on **1300 066 055**.

**MORE INFORMATION
ARF AND RHD**

www.rhdaustralia.org.au



NSW Rheumatic Heart Disease Register

Information for patients with
Acute Rheumatic Fever (ARF) or
Rheumatic Heart Disease (RHD)
and their families



What is the Register?

- ♥ People with ARF or RHD need regular penicillin needles to stay healthy and keep their heart strong.
- ♥ The Register is a list of people with ARF and RHD in NSW. People on the Register can be sent information and messages to support them on their treatment journey.
- ♥ Before we include your name on the Register we ask for your permission.
- ♥ For children under 14 years, we ask the permission of a parent or primary caregiver to include the child's name on the Register.

What information does the Register collect?

- ♥ Your name, date of birth, address and contact details.
- ♥ For children, the contact details of a parent or primary caregiver.
- ♥ Important dates including:
 - when you have been sick with rheumatic fever
 - when you receive your treatment (needles)
 - when and where you see your health care team.
- ♥ Important heart tests or operations.

Who can see my information?

- ♥ Only the health team looking after you will know that your name is on the Register. This includes:
 - staff who manage the Register.
 - doctors, nurses and Aboriginal health workers at your clinic.
 - heart specialists or other doctors caring for you.
- ♥ If you travel to another state or territory, information you have provided may be given to their health service. This is so that you can continue your treatment.
- ♥ If your health team loses contact with you, we may send your name, date of birth and contact details to Medicare Australia to find out your current address and try to re-contact you. None of your health information will be sent to Medicare Australia.
- ♥ Information from the Register will also be sent to a national system that monitors RHD in Australia. This information will not include your personal details.

