

NSW Acute Rheumatic Fever & Rheumatic Heart Disease Register

Advice for clinicians seeking consent for the Register

What is the NSW ARF and RHD Register?

The NSW Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) Register was established to improve the long-term clinical care and follow-up of people with ARF and RHD. Joining the Register is voluntary and anyone living in NSW diagnosed with ARF or RHD is eligible to be on the Register. The Register supports a patient's ARF and RHD care by communicating with their GP and other health professionals in NSW and interstate.

What are the benefits of the Register?

- Evidence overseas shows that registers increase scheduled secondary prophylaxis injections and assist in maintaining the long-term management of a patient's care.
- Supports transfer of patient care to another local health district, interstate or overseas either temporarily or permanently.
- Supports clinicians with treatment reminders (if required), updates to clinical management guidelines, and accessing NSW Health services.
- Improves understanding of the burden and health system requirements of ARF and RHD in NSW.

What information does the Register collect?

The register collects:

- patient and primary care provider contact information,
- dates of medical or specialist reviews, echocardiograms, and secondary prophylaxis injections,
- details of heart valve surgery.

What happens to the information on the Register?

The Register supports a patient's ARF and RHD care by communicating with their GP and other health professionals in NSW and interstate. If a patient is no longer contactable by their GP or the Register, the Register will follow-up with Medicare for the patient's most recent contact details.

Deidentified information is also sent to the Australian Institute of Health and Welfare for ARF and RHD reporting in Australia.

Why do I need to seek consent with the patient?

It is important for a health care professional to discuss consent with the patient to ensure they are informed and to explain the benefits to their clinical care. If consent is not given by the patient the case will not be entered on the Register. All diagnoses of ARF, and RHD in people under the age of 35 years, are recorded in the NSW notifiable diseases system as required by the *Public Health Act, 2010*.

How do I seek informed consent?

For a patient to provide informed consent they must understand the risks and benefits of having their information collected by the Register.

We recommend that you:

1. Use the patient Register brochure
<https://www.health.nsw.gov.au/Infectious/rheumatic/Publications/rhd-information-brochure.pdf>
2. Use key cultural health workers where appropriate
3. Ensure the patient understands:
 - a) What the Register is
 - b) The benefits of the Register
 - c) What information is collected and what happens to that information
 - d) That consent is voluntary, and they can withdraw at any time.

Consent forms

4. Consent forms are available on the NSW Health website.
<https://www.health.nsw.gov.au/Infectious/rheumatic/Pages/consent.aspx>
5. There is a consent form for patients over the age of 14 that can self-consent, and one for patients under the age of 16 where a parent or guardian is consenting. Verbal consent is acceptable if the patient is not comfortable signing the form or if you are discussing it with the patient or their guardian on the phone or during a telehealth appointment.

Next steps

6. Provide an update on the outcome of your discussion about consent, including completed consent forms, to your local PHU or the NSW RHD Program.
7. **Local PHU:** 1300 066 055
8. **NSW ARF and RHD Register:** email (NSWH-RHD@health.nsw.gov.au), fax (02 9391 9189), or phone (02 9391 9195)

Further information

Further information on the NSW Health Rheumatic Heart Disease Program can be found on the NSW Health website. <https://www.health.nsw.gov.au/Infectious/rheumatic/Pages/default.aspx>

Information on the diagnosis and management of patients with ARF and RHD is available in the 2020 *Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease, 3rd edition* www.rhdaustralia.org.au/arf-rhd-guideline