



WA Rheumatic Heart Disease Register

Patient advice

Do you have, or are you being treated for Acute Rheumatic Fever or Rheumatic Heart Disease?

There are laws that affect you

Regulations are in place to maintain the **Rheumatic Heart Disease Register of Western Australia (the register)**.

The register identifies and records all known cases of Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) in Western Australia.

Health workers have a legal duty to provide information on a patient when they become aware that the patient has, or is being treated for, ARF or RHD.

How will the regulations affect you?

The regulations **will** apply to you if you have, and are being treated for, ARF or RHD. This means that information, tests and reports about you and your condition will be kept by the register.

What information will be collected?

Information collected will include:

- copies of echocardiograms (ultrasound of heart)
- reports from cardiologists and other specialists providing expert opinion on treatment and progress
- list of penicillin injections given for ARF and RHD
- details of which health service provides your health care
- recommended due dates for specialist review and treatment.

All information provided to the register is confidential

What will information collected about your condition be used for?

Information provided to the register will be used to monitor and improve:

- treatment
- access to medical specialists and echocardiograms
- research and data collection into causes, prevention, treatment and screening.

Will your information be shared?

In certain circumstances, your information may be shared with:

- a healthcare worker to provide a personal clinical history
- approved researchers for medical research
- the National Coordination Unit – a nationally funded body set up to coordinate the response to RHD in Australia.

Can you access or remove your information from the register?

You can access your information. You have a right to the information held about you on the register.

You can't be taken off the register, but you can request limited disclosure of all identifying information.

To find out what information is held, to access a copy, or request limited disclosure of identifying information, you must contact:

WA RHD Register and Control Program

RHD.Register@health.wa.gov.au

Phone: 1300 622 745

If you have a legal disability, or are under 18 years old, a parent/guardian can make a request for you.



This document can be made available in alternative formats.

Produced by WA Country Health Service
© Department of Health 2025

Copyright to this material is vested in the State of Western Australia unless otherwise indicated. Apart from any fair dealing for the purposes of private study, research, criticism or review, as permitted under the provisions of the *Copyright Act 1968*, no part may be reproduced or re-used for any purposes whatsoever without written permission of the State of Western Australia.