



Do you have, or are you being treated for Acute Rheumatic Fever (ARF) or Rheumatic Heart Disease (RHD)?

There are laws that affect you

Regulations have recently been introduced that create and maintain a **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 now have a legal duty to provide particular 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.

All information provided to the register is confidential

For further detail on the type of information kept by the Register, see the table on the next page.

What will information collected about your condition be used for?

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

- Treatment of ARF and RHD
- Access to medical specialists and specialised heart tests called echocardiograms (ultrasound of heart)
- Research and data collection into causes, prevention, treatment and screening of ARF and RHD

Will your information be shared?

Your information may be shared, but only in certain circumstances.

Your information will only 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 rheumatic heart disease 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 *write* to the WA RHD Register and Control Program. PO Box 525, Broome 6725 or email RHD.register@health.wa.gov.au

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 on request for a person with a disability.

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