SA Rheumatic Heart Disease (RHD) Register

For health professionals

Background of the RHD register

> The most effective approach to controlling rheumatic heart disease (RHD) is through regular injections with long acting benzathine penicillin G (BPG), known as secondary prophylaxis, for all people with a history of acute rheumatic fever (ARF) or RHD.

> Registers of people with a history of ARF or RHD can improve the delivery of secondary prophylaxis and are an important element of control programs. The RHD register can assist individual health services and health professionals in the management and follow up of local patients with ARF and RHD, as well as provide important epidemiological data for SA.

> The SA RHD register records cases of ARF (initial, recurrent or probable episode) and RHD (definite and borderline) based on the case definitions outlined in the Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition), accessible from http://www.rhdaustralia.org.au/.

> Consent is required before a patient’s details can be included on the register. Refer to attached consent form and fact sheet for patients. Parents or guardians of children (<16 years) with a history of rheumatic fever or rheumatic heart disease are required to consent to their children’s details being included on the register.

> Patient education about ARF and RHD is an important part of the consent process and this is noted on the consent form. RHD register staff can assist with the provision of resources or further education if required.

How are data collected?

> Data are collected according to national standards, using the RHDAustralia ARF and RHD (clinical) data set specifications.

> Initial data come from the notification form at time of diagnosis.

> Information on this episode or subsequent reviews may then be obtained (with the patient’s consent) by SA RHD register staff. Subsequent information may be provided to the SA RHD Program via copies of echocardiography reports, information retrieved from medical records, being copied into correspondence letters from specialists or directly requesting information by phone/letter to specialists’ rooms.

> Health professionals involved in the direct care of patients with ARF/RHD provide information to the register about secondary prophylaxis by entering it straight onto the register or sending information from their patient management system in to the register.
Fact Sheet

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Who has access to information on the register?

> SA RHD Program staff (within Communicable Disease Control Branch, SA Dept of Health)
> Health providers who are involved in the direct care of patients on the register, including:
  > Primary health care staff and Aboriginal health workers
  > Cardiologists, including those from Alice Springs Hospital
  > Paediatricians, physicians, obstetricians and other medical specialists
  > Relevant dental practices
> If a patient moves or travels to Northern Territory, Queensland or Western Australia, their information may be provided to the RHD Register in these states for continuity of care.

How do I get access to the register?

> The RHD register is accessible via any computer that has internet access.
> Access is available to individual health professionals, subject to specific restrictions.
> Access is password protected and is reset at twelve month intervals.
> Access to the register provides the ability to read patient information and to enter data and/or comments relating to the delivery of secondary prophylaxis in their clinic.
> Access is granted by completing the ‘SA RHD Register Access’ Application Form.
> Only eligible staff who have read the register policy statement, agreed with the terms of the policy and signed the Access Application Form can access the register.

For more information

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www.ausgoal.gov.au/creative-commons
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