



Consent for the NT Rheumatic Fever / Rheumatic Heart Register

Points to be explained to the patient by the person obtaining consent:

1. The story:

- Rheumatic fever and rheumatic heart disease are big problems for Aboriginal people. It can be stopped or from getting worse by having penicillin needles every 3-4 weeks.
- A list (or register) of people with rheumatic fever and rheumatic heart disease helps clinics to remember the time for needles and when people need to see the doctor.
- Before people's names go on the list, we would like to ask for their permission.
- Parents of children (<18 years) with rheumatic fever or rheumatic heart disease should be asked for permission for their children to be on the list.

2. Information collected for the list (register):

- Your name, date of birth, where you live and your people.
- The dates you have been sick with rheumatic fever/rheumatic heart disease
- When you first needed needles and how often you get them.
- When you see the doctor about rheumatic fever or rheumatic heart disease (RHD).
- Any heart tests or operations you have had.

3. The list is used by:

- Community clinics to remind them about needles and appointments.
- The health people in Darwin to check how rheumatic heart prevention is working and to train new staff for the clinics.
- Dental Clinic. The list will be used so the dentist knows if he needs to see you. It is very important that people with rheumatic heart have a good healthy mouth and teeth because this can affect the heart.
- Doctors to learn about rheumatic heart. (Sometimes doctors will want to catch up with people whose names are on the list to see if they can find out more about this sickness. Doctors may contact you in the future for this purpose if you give permission.)

4. Who can see the list of names?

- Only the people looking after the list and the clinic staff who look after you will know the names on the list. It will not be shared with people who are not looking after your treatment or follow-up.

5. Who else can have your information:

- If you move or travel to South Australia; Queensland or Western Australia information you have provided may be passed on to the RHD Register in these states if you give permission. The information is passed on so they are able to continue your treatment and follow-up while you are in their care.

6. How long will information be kept:

- Your name and information will stay on the list unless you ask for it to be taken off.

THIS IS FOR YOU TO KEEP

If you have any worries or questions contact the Clinic, or call
The Rheumatic Heart Disease Register

TOP END

Email: RHDDarwin@nt.gov.au

Bld 4, CDC, Royal Darwin Hospital

PO Box 40596

Casuarina NT 0811

Fax: 08 892 28277

CENTRAL AUSTRALIA

Email: RHDAliceSprings@nt.gov.au

CDC, Alice Springs Hospital

PO Box 721

Alice Springs NT 0871

Fax: 08 8951 6920

**Rheumatic Fever / Rheumatic Heart Disease Register
CONSENT**

(Please complete this form when consent is requested)

We would like to make sure that you know as much as you want about rheumatic fever and rheumatic heart disease.

- I understand English
- I have watched the rheumatic heart disease DVD
- I have read the rheumatic heart disease pamphlets
- I would like more information on rheumatic fever and rheumatic heart disease

If you are happy to be included on the Rheumatic Heart Disease Register after reading the attached information sheet, please tick the boxes below:

- I agree for my name and information to be on the Rheumatic Heart Disease Register
- I agree for my name to be given to doctors who might want to catch up with me to learn more about this sickness.
- I agree that if I move or travel to other states my information can be passed on to RHD Registers in those areas so they are able to provide me any follow-up treatment and care that I may need.

Patient's name:

Signature of Patient:

Signature of Parent or Guardian (if patient under 18 years of age):
.....

Relationship to patient:.....

Patient's DOB

Patient's community.....

Name of person obtaining consent:

Signature of person obtaining consent:

Date...../...../.....

I.....an interpreter / Aboriginal or Aboriginal and Torres Strait Islander Health Practitioner have explained to.....(patient's name) the information in this form.

Additional Information

1. For a child (person under 18 years) please obtain consent from a parent / guardian.
If the patient requires more information, please discuss their needs with them before they sign the consent sheet.
2. If the patient is unable to sign (i.e. cannot write) but wishes to be registered then obtain verbal consent and document that consent in writing and attach that note to this consent form.
3. When consent has been obtained, please inform the RHD register by sending or faxing a copy of the consent sheet and any note to the address provided below, or by calling the number provided below.

PLEASE OFFER THE FACT SHEET TO THE PATIENT

TOP END

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