

NSW Health

Understanding experiences of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) for Pasifika people in NSW

INFORMATION FOR PARTICIPANTS

NSW Health is conducting this research project. The research team includes staff from the NSW Rheumatic Heart Disease Program and Pasifika health workers from Western Sydney and South Western Sydney Local Health Districts.

What is the purpose of the study?

The purpose of the study is to listen to and understand the experiences of Pasifika people and families with acute rheumatic fever (ARF) or rheumatic heart disease (RHD). The information you share will be used to improve the way NSW Health supports people with ARF and RHD.

Who is invited to participate?

You may have heard about this project through a Pasifika health worker or community groups. Families with a person diagnosed with ARF or RHD may directly contact the researchers to participate. You may have been invited because you have previously agreed (via your doctor or hospital) for you or your child to be included on the NSW RHD Register. The Register is voluntary and anyone living in NSW diagnosed with ARF or RHD is eligible to be on the Register.

What's involved?

You will have a conversation with a Pasifika health worker for between 30 – 60 minutes. The health worker will ask you about your family's experience of ARF/RHD. You are welcome to bring other people with you. The conversation can be in English, Samoan, or Tongan. The conversation will happen at place that is convenient for you and the health worker and will be recorded. The conversation can be done online if you prefer, or if you live outside of Sydney.

Do I have to take part?

No. You don't have to take part if you don't want to. Your decision will not affect the care you or your family receives. If you agree to participate but change your mind later, you can withdraw at any time up until 2 weeks after the conversation.

What will happen to what I say?

The recording of the conversation will be typed out into a written version. This will not include any names. The researchers will read what was said and summarise the main ideas. The main ideas will then be combined with the main ideas from conversations with other families, to produce a final report.

How will my privacy be protected?

The research team will not tell anyone whether you participate. The recording will be stored securely by the NSW Ministry of Health, and once the conversation has been typed up the recording will be permanently deleted. The written version (transcript) will be stored securely by NSW Health for five years and then permanently deleted. The transcript will never be published. We may use some of your ideas or words in the reports or publications that we write without using you or your child's name.

We will never include your name or any other information that identifies you or your child in any reports or publications. The research team will never disclose your information without permission, except when required by law (e.g. if ordered by a court) or where we believe it is necessary to prevent a serious threat to anyone's safety.

What are the benefits?

Participating will not immediately benefit you or your family member. Sharing your family's story will help NSW Health understand the experience of people living with ARF/RHD. This will help NSW Health improve the way it supports Pasifika people with ARF/RHD. You will receive an \$80 gift card after the interview.

Are there any risks?

During the conversation, you will be asked about you or your family member's experience of living with ARF or RHD. This may be upsetting. You do not have to answer any questions if you do not want to.

What do I do if I would like to go ahead?

Please contact Yvonne Peacock, Health Program Officer – Pacific Communities on 9881 1259 or 0409 346 210 to book a time and place for the interview. You can also contact Yvonne Peacock to ask any questions about the project.

What should I do if I have concerns about the study?

This study has been approved by the NSW Population and Health Services Research Ethics Committee (PHSREC) and Western Sydney Local Health District (WSLHD) Research Governance office. If you have any concerns or complaints about the research you can contact the PHSREC Executive Officer at cinsw-ethics@health.nsw.gov.au and quote the

reference (2024/ETH00779) or the WSLHD Research Governance Office by telephone on 02 8890 9007 or email Wslhd-researchoffice@health.nsw.gov.au.

What should I do if I would like to leave feedback for Western Sydney Local Health District?

Your experience is important, your feedback helps us know what we are doing well and where we can improve. If you would like to raise a concern or complaint about Western Sydney Local Health Services, please contact the patient experience unit by telephone on 02 8890 7014 or via email Wslhd-westmead-feedback@health.nsw.gov.au.