Participant Information Sheet

Your letterhead

RHD Echo Screening: Sustainable Workforce Sub-Study

PI and contact details:

Ethics committee ref:

Kia ora, Talofa, Mālō e Lelei, and Warm Pacific Greetings,

You are invited to take part in this qualitative study (wānanga/talanoa or interview) exploring and documenting staff perspectives on sustainable workforce planning for RHD (rheumatic heart disease) echo screening. This sub-study is being conducted as part of the RHD Echo Screening study, to help the study team assess the workforce model and make recommendations for a national RHD echo screening programme.

This participant information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as whānau, friends, or colleagues. You may also wish to talk more with your manager. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document.

VOLUNTARY PARTICIPATION

Participation is completely voluntary. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect your current or future work or role in the study in any way. The choice to do so is at the discretion of each staff member. Other members of the team will not be provided with any information about your participation.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to identify and assess workforce models that will support the delivery of a future national echo screening programme for RHD. These wānanga and interviews are an important part of assessing the workforce model.

HOW IS THE STUDY DESIGNED?

The study is qualitative with wānanga/talanoa groups or interviews arranged in work time.

WHO CAN TAKE PART IN THE STUDY?

All staff who have worked in the RHD clinics.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

We will arrange a time to coincide with the completion of screening clinics at each site (Counties, Bay of Plenty and Lakes) while the clinic team are together. If you choose to have an individual interview instead, these will be arranged at a time that suits you and can be in person or virtual. Interview and wānanga groups may be 20-60 minutes. The group or interview is transcribed, a transcription copy will be sent to participants to enable corrections to their own contribution (where it does not impact on others contributions).

The kind of topics that may be covered include:

- perspectives on the advantages and disadvantages of heart screeners with sonography supervision
- discussion on factors to increase cultural safety for rangatahi and their whānau throughout screening process
- barriers and enablers of task sharing
- perspectives on success of school-based screening vs school plus community
- acceptability and cultural acceptability of heart screener led echo clinics from a kaimahi perspective
- consent and assent conversations
- Invitation and engagement approaches, contactability, what works and what it takes to reach participants

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

There are expected to be minimal risks in the interview and focus groups. Participants only describe what they feel comfortable talking about. You may decline to answer a question, and you may pause or step out of the focus group or interview if you wish.

The data will not be presented for dissemination with any identifying details, and participants will be assigned study codes, however because the screening teams are relatively small with some key defined roles it is possible that you may be identifiable. The information from your interview or group will be combined with that from other sites to help mitigate this risk as much as possible.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

The main benefit of the study is sharing of expertise and lessons learned with others interested in RHD work, locally and internationally. Task sharing is currently a focus for many professions, and it is likely that this work will be able to apply to other health services and workforce development, particularly for Māori and Pacific communities. It may also feel positive to be able to describe what you have learned in your work, and about your contributions and how the work might be improved.

WILL ANY COSTS BE REIMBURSED?

We will meet during work hours and as close to the completion of screening clinics as possible, kai will be provided. For kaimahi who have travelled to support clinics, interview via phone or videoconferencing will be offered.

CAN PARTICIPANTS CHANGE THEIR MINDS OR WITHDRAW FROM THE STUDY?

If you do want to take part now, but change your mind later, that is completely fine. You can withdraw your consent to participate by informing the study contact listed below up until the point at which your information becomes part of the analysis. You can refuse to answer any particular question within the focus groups or interviews, and you can ask for the recording to be turned off at any stage.

You have the right to request access to your information. You also have the right to request that any information you have contributed is corrected. You can request to withdraw any information given during an interview, however as focus groups, wānanga and talanoa rely on discussion, reflection and interaction between participants removal of your contribution after the group could have an impact on the understanding and context of the rest of the transcript.

DATA SOVEREIGNTY

Māori data sovereignty is about protecting information or knowledge that is about (or comes from) Māori people. We recognise the taonga of the data collected for this study, to help protect this taonga:

- We have senior Māori researchers involved in the collection, ownership, and use of study data and have undertaken a Māori Data Sovereignty audit.
- The Hauora Māori Directorate and Pacific Health Senate in Health New Zealand, Te Whatu Ora are providing oversight of this study.

If you would like more information about how the study team is ensuring Māori data sovereignty, please contact us on the study team details below.

WHAT WILL HAPPEN TO MY INFORMATION?

<u>De-identified (Coded) Information</u>

To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the study team and/or any study information sent to the sponsor of the primary study. Instead, you will be identified by a code. The group facilitator/interviewer will keep a list linking your code with your name, so that you can be identified by your coded data if needed.

The following groups may have access to your **coded** information:

- The sponsor and steering group, for the purposes of this study.
- The study team (up to 10 people) who will be supporting analysis and write up of this sub-study.

The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

Recordings will be transcribed and then destroyed. Transcripts will be stored in a secure place within Health NZ Te Whatu Ora drives, with participant codes and no identifying details. They will be stored for up to ten years. Participant consent forms will be stored securely separate from the transcripts in a password protected folder.

Participants will be offered the transcript and can ask for changes to their contribution.

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information (e.g. making it harder for you to get or keep a job or health insurance) is currently very small, but may increase in the future as people find new ways of tracing information.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name, position
Telephone number
Email

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@advocacy.org.nz
Website: https://www.advocacy.org.nz/

Māori cultural support: *To be locally nominated*

Name, position
Contact

Pacific cultural support: *To be locally nominated*

Name, position
Contact

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Email: hdecs@health.govt.nz
Phone: 0800 400 569 (Ministry of Health general enquiries)

Consent Form

Your letterhead

RHD Echo Screening Sub-Study: Workforce Sustainability

Please tick to indicate you consent to the following

I have read the participant information sheet, or have had it read to me in a language I understand, and I fully comprehend what it says.	Yes ☐	
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study up until the point of data analysis without this affecting my workplace relationships.	Yes ☐	
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes ☐	
I agree that I will maintain the confidentiality of other participants in this group and will not discuss the contribution of others outside of the focus group.	Yes ☐	
I am aware that I will have the opportunity to review transcripts, however I may not be able to change or fully remove information where this impacts on the contribution of others.	Yes ☐	
I know who to contact if I have any questions about the study in general.	Yes ☐	
I would prefer to set up an individual interview time	Yes ☐	No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____