

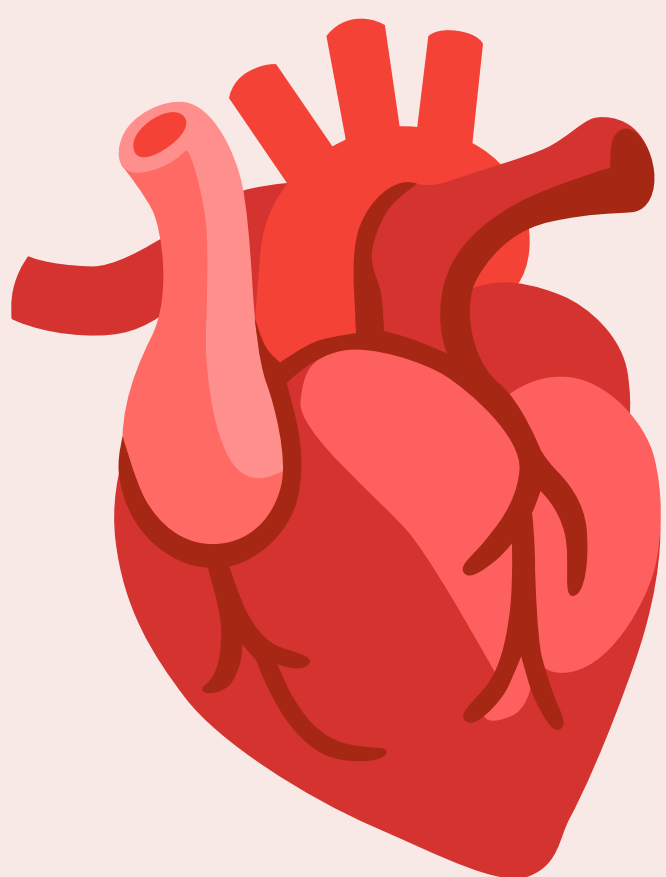
Developing Culturally Appropriate and Accessible Research Documentation

The 'Genome Sequencing in Cardiovascular Inherited Diseases' Project

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Whaingā | Aim

Update the existing study protocol and research documentation to be more culturally appropriate, approachable, and easier to understand, to achieve true informed consent and maintain tino rangatiratanga for participants.

Whakatakinga | Background

Genetic testing for cardiovascular diseases can help to confirm or refine a diagnosis, inform prognosis, guide treatment and, most importantly, to initiate cascade testing. Cascade testing refers to testing at-risk whānau who aren't yet affected by the condition, which leads to preventative care. However, there is a lower diagnostic yield for Māori and Pacific peoples in Aotearoa with cardiovascular inherited disease (CID), who therefore miss out on the benefits of genetic testing/cascade testing.

The 'Genome Sequencing in Cardiovascular Inherited Diseases' project was established to identify novel genetic variants that cause CID in Aotearoa, with a focus on improving health outcomes for Māori and Pacific whānau. A Māori governance group, Kaitiaki Rōpū, which includes Māori cultural and scientific experts and CID whānau was established to ensure cultural appropriateness of the project and emerging narratives for Ngāi Māori. They also offer feedback and advice on the development of research documentation.

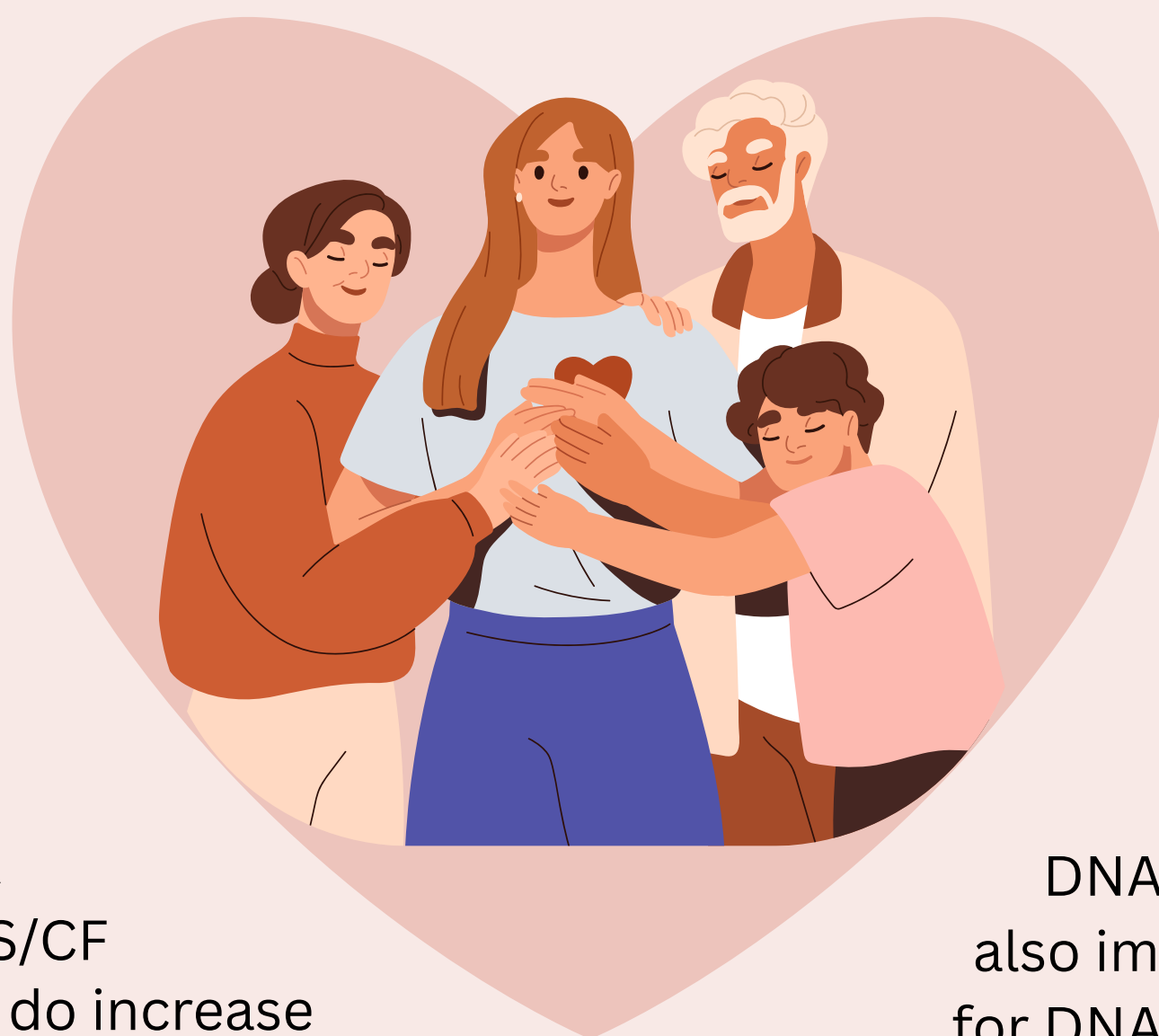
Te Ara | The Process

Documentation:

We reviewed the existing Participant Information Sheets, Consent Forms (PIS/CF) and study protocol with input from Māori data sovereignty experts, community members, and multiple hui with the Kaitiaki Rōpū.

Text was simplified and shortened using Microsoft Copilot (AI tool) and by review. Shorter/simpler PIS/CF are not likely to increase recruitment success, but do increase participant comprehension and retention of information.

Te reo Māori was included throughout the text and simple graphics were developed using Canva to appeal to the reader, which draw on Māori motifs. Hei taurira



Recommendations to adjust the study protocol:

Whānau support was important for some participants. Consenting begins with asking if whānau support is preferred and if there are any tikanga, eg. karakia, whakanoa, required for consenting and/or sample donation/storage/disposal.

DNA remaining in Aotearoa was also important to some. The option for DNA sequencing to be done in Aotearoa has been developed to maintain rangatiratanga for the participant by allowing a choice.



A Tairāwhiti-specific explanatory video was developed with the recommendations of Tairāwhiti community members. The video is short (2 mins 50 secs) and will appeal to visual learners and participants who opt out of reading the PIS/CF.

Anei te hononga pae tukutuku (video link)



The video was reviewed by Tairāwhiti community members and the kaupapa Māori research rōpū from Manawaora | The Centre for Health. Still to be reviewed by clinicians.

Hei Whakakapi | Summary

We have developed improved, tailored information to support participation of Māori participants in this research. Inclusive research design requires collaboration between researchers, cultural advisers and the wider community. Māori governance groups, such as the Kaitiaki Rōpū, offer essential perspectives on accessibility and cultural appropriateness.

Tēnei te mihi ki a Pūtahi Manawa (funding provider) mō ngā pūtea me te korahipi hoki kua koha mai, anō hoki ki te hapori whānui kua tautoko i te kaupapa nei.