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2023

## Special Project: An Evaluation of the Co-Design Process of the Pūtahi Manawa Integrated Research Modules

## **Grant Call for Proposals**

#### Background:

The mission of the Pūtahi Manawa | Healthy Hearts for Aotearoa New Zealand (HHANZ) Centre of Research Excellence (CoRE) is to improve equity in heart health for Māori and Pacific Peoples through research excellence and precision medicine. Pūtahi Manawa will bring together research scientists, clinicians, educationalists and communities by comprehensively and collaboratively addressing issues around equity in heart health outcomes to support and complement the public health approach. We wish to work in partnership with communities and researchers to create a vibrant world-class environment and network for heart research in Aotearoa New Zealand that is underpinned by evidenced based, multi-disciplinary collaborative research that delivers clinical benefits and heart health equity to patients.

### About the Special Project Grant:

#### Purpose:

To evaluate the co-design process and experience of researchers and the communities during the implementation of the Pūtahi Manawa flagship research projects – the Integrated Research Modules (IRMs).

#### Rationale:

Research has historically been conducted "on" rather than "with" communities of interest, creating mistrust and contributing to inequitable outcomes. Internationally, community engagement or Patient Public Involvement (PPI) is becoming a standard practice to actively work in meaningful partnerships with members of the public in order to create a health and research environment that is responsive to evolving patient needs and values.

While co-design has been adopted in Aotearoa New Zealand, there is little evidence around best practice for conducting co-design for health research in Aotearoa, in an interdisciplinary way. Pūtahi Manawa understands the importance of community voice and agency in the research process but this is not current standard practice. It is our intent to operationalise this 'business not as usual' (BNAU) approach to research within the delivery of the IRMs over the next three years.

In order to create long term trust with the public, Pūtahi Manawa would like to hear from co-design communities about their experience with the IRM teams along this journey of co-design during the life-course of the IRM. Through this iterative process, there is an opportunity to hear from our communities so that our colleagues in health and research can provide mana-enhancing experiences in co-design led research. This will lead to real-world solutions for the real-world, holistic issues of our patients.



#### Aims:

- Understand the experience of engagement and co-design from the perspective of communities to inform a best-practice processes by research and health practitioners
- With communities, determine a set of principles for engagement and co-design that support mana-enhancing experiences for communities involved in research to form the basis of an Aotearoa based "Gold Standard" of co-design for health
- Describe and document case studies of Pūtahi Manawa researchers who are undertaking this BNAU journey in their research to understand their "why". This will help to inform how one may engage other researchers to adopt a BNAU approach in future. BNAU principles of research are considered to be:
  - o Equity
  - o Te Tiriti
  - o Community engagement
  - o Co-design
  - o Multidisciplinary

Applicants should have a track-record in bench-marking/evaluation work, strong national networks and a clear plan for disseminating their findings to researchers and communities.

#### Outputs:

Outputs should include all or most of the following:

- 1) Guidelines for researchers undertaking community engagement and co-design
- 2) A process roadmap for researchers, based on case studies which will cover how to, and considerations for, undertaking research that upholds BNAU principles of research above
- 3) Resources that will support communities to enact tino rangatiratanga (self-determination) as partners in research
- 4) Peer reviewed academic publications
- 5) Education sessions/workshops at appropriate events

#### Grant duration and funding:

The grant will support 3-year period. The grant is up to a maximum of \$500,000.

#### Eligibility:

All proposals should be aligned with our Pūtahi Manawa | HHANZ CoRE principles as outlined below in the Special Project Criteria section.

Pūtahi Manawa will accept applications from teams not already participating in any other Pūtahi Manawa funded research project.

Research teams should not include anyone already part of a research team in the Pūtahi Manawa Integrated Research Modules.

Projects can only be awarded to teams based in Aotearoa New Zealand.

#### **Kev Dates:**

Call for Proposals: 21 June 2023 Proposals due by: 31 July 2023

Short list results announced for presentation to the panel: August 2023

Presentation: August 2023

Final results: August/September 2023 Project start date: September 2023



#### Budget:

Please use the attached budget template, instructions are provided. Maximum grant value is \$500,000.

### Special Project Criteria

|                 | Definition   |
|-----------------|--|
| Evaluation      | Describe the methodology used to evaluate IRM co-design and                |
| Processes /     | engagement processes, and community and researcher experiences             |
| Research Plan   | How robust is the methodology?   |
|                 | Evidence of peer review?   |
|                 | Please describe the 3-year research plan, with objectives and timelines    |
| Reporting Plan  | Describe how the outputs listed in RfP will be achieved (including         |
|                 | timeline)  |
|                 | Describe the dissemination plan for community, researchers and             |
|                 | Pūtahi Manawa CoRE members (How will this project engage with the          |
|                 | community and stakeholders?)   |
| Te Tiriti o     | Provide evidence of upholding equity and Te Tiriti in the project plan and |
| Waitangi /      | team   |
| Equity          | How does the proposal include a Te Tiriti o Waitangi focus?                |
|                 | How is Māori partnership/leadership/governance included?                   |
|                 | How is Pacific partnership/leadership/governance included?                 |
|                 | How does the proposal acknowledge both Māori and Pacific cultural          |
|                 | beliefs, values, practices?  |
|                 | Is data handling culturally appropriate? (i.e. is there a data governance  |
|                 | strategy)  |
| Research and    | Provide evidence and experience of engaging with Māori communities         |
| Community       | and Pacific Communities  |
| Networks        | Show understanding and evidence of interfacing between researchers         |
|                 | and community  |
|                 | Provide evidence of strong national networks                               |
| Team Excellence | Tell us about your team.   |
|                 | Describe experience in co-design and community engagement                  |
|                 | Describe experience in benchmarking and evaluation                         |
|                 | Describe diversity and track record (relative to opportunity) of project   |
|                 | team   |

#### Scoring and Weightings:

- Section A: 40% Evaluation Processes/Research Plan 20%; Reporting Plan 20%
- Section B: Te Tiriti/Equity 20%
- Section C: 40% Research and Community Networks 20%; Team Excellence 20%

#### Conditions:

Researchers must be based in Aotearoa New Zealand.

#### How to apply:

Please send the completed application form, your budget, and NZ RS&T CVs to: hhanzcoregrants@auckland.ac.nz unless your institution / organisation requires you to work with your local research office to submit on your behalf. For example, this applies to the University of Otago and the University of Auckland.

#### Contact information:

hhanzcoregrants@auckland.ac.nz



## Integrated Research Module Summaries Introduction

Research has typically operated in speciality silos in health. These silos have hindered collaboration and innovation and can lead to duplication of work and a competitive environment. The drive behind the Creation of Integrated Research Modules (IRMs) was to create programmes of work where collaboration and multidisciplinary is the major focus across heart health research, to address equity in heart health outcomes. IRMs as programmes of work are also designed to involve communities and whānau from the outset to ensure the work being done is relevant and beneficial to the people who Pūtahi Manawa are trying to have the most impact for. Below we describe five projects that are to be evaluated as part of the Special Project.

# Sweet pressure: Improving outcomes for people with diabetes and high blood pressure in Aotearoa

Primary Investigator: Dr Fiona McBryde, University of Auckland

Most adults with diabetes also have high blood pressure and about half of people with high blood pressure don't have good blood sugar regulation which can lead to diabetes. Good control of both high blood sugar and high blood pressure ('Sweet Pressure') is essential for reducing risk of heart attacks and strokes.

In current health care, diabetes and high blood pressure are managed as different conditions. This programme of work will look for common links between the mechanisms regulating blood pressure and blood sugar. We propose to co-create a research programme in a collaboration between communities impacted by Sweet Pressure and our research scientists.

Depending on the priorities raised by our Sweet Pressure communities the co-created research programme may include discovery studies to investigate mechanisms and identify new treatment targets, and/or interventional studies of novel approaches to specifically address and improve the management of Sweet Pressure.

We will co-create an outreach and education program to raise awareness about the dangers of Sweet Pressure and how to identify its presence. Our ultimate goal is to achieve improved and more equitable outcomes for people with Sweet Pressure in Aotearoa.

### Te ara Poutama: Living well with heart disease Primary Investigator: Ms Erina Korohina, The Centre for Health

Te Ara Poutama is a Hapori Māori-led Heart Health Research Programme, which is foundational for developing culturally grounded approaches to equitable Māori heart health.

The main anticipated outcomes include:

- establishing Pūtahi Manawa's first Kaupapa Māori Heart Health Research Programme, that has meaningful Māori engagement embedded throughout
- the training of 30 Māori into the multidisciplinary heart health workforce
- co-designing, with Māori whānau living with heart disease, solutions from their lived experiences
- gaining unique and important insights to factors that contribute to heart disease amongst Māori and identifying the burden of heart disease for Māori including social, cultural, whānau, spiritual, emotional, psychological, and physical impacts, to enable improved Māori heart health.

Taken together these outcomes have the potential to significantly improve Māori heart health in meaningful ways



# Ō tātou ngākau, ō tātou ira, ō tātou korero / Our heart, our genes, our story Primary Investigator: Dr. Polona Le Quesne Stabej, University of Auckland

Inherited heart diseases are a major cause of sudden unexpected death in young people. The genetic causes of these conditions have been researched for decades, but answers are found for less than half of patients. The chance of a genetic diagnosis is even less for patients from ethnic minority populations (including Māori and Pacific) because research has historically been biased to European ancestry and genetics. The purpose of this project is to find answers for families in Aotearoa where European-based genetic tests have failed to find a cause.

We propose that genome sequencing, looking at all 3 billion DNA letters, can find previously unknown genetic changes causing inherited heart conditions. By finding the disease-causing genetic changes that whānau may carry, we can:

- Raise community awareness of the power of gene sequencing to prevent sudden cardiac death
- help transform their healthcare through earlier detection of whānau members who may be carriers of the disease-causing gene,
- improve diagnosis of heart related genetic problems,
- in some cases, provide genetically guided treatment and counselling

This project will serve as a model to support genome sequencing as a regular part of clinical practice.

# Restoring the balance: Heart health of wāhine, Fafine, Va'ine, Fifine and Women in Aotearoa

#### Primary Investigator: Prof. Johanna Montgomery, University of Auckland

In 2019, 275 million women were diagnosed with heart disease, with heart disease the cause of 35% of all deaths in women worldwide. Yet as summarised in a 2021 report commissioned by the leading Lancet medical journal, "Cardiovascular disease among women is understudied, under-recognised, underdiagnosed, and undertreated globally."

In Aotearoa, the bleak reality is that heart health inequities experienced by women are even more significant for Māori and Pacific women. It is shameful that we are in this position at the start of the 21st century. Our research programme aims to restore the balance by authentically engaging with communities in co-design cycles to work together towards heart health equity in Aotearoa.

#### Specifically, we will

- create a heart health kete (basket of knowledge) via co-design with Māori and Pasifika communities to generate knowledge discovery, transformation and dissemination of heart health knowledge
- produce 'uniquely Aotearoa' perspectives papers to document heart health considerations and inequities across the life-course of NZ wāhine
- generate new knowledge of female-specific cardiovascular risk factors by analysing existing data and developing new datasets to inform new research, and to improve accuracy of heart disease risk prediction for women
- acknowledge and consider the unique heart health environment for transgender people through community connection, engagement and co-design
- support the workforce development of wāhine via educational and career development opportunities.

Our overall goal is, to amplify the mana wāhine voice and change the way that heart health research is conducted in Aotearoa/New Zealand.

## Working towards heart health equity for Pacific Peoples Primary Investigator: Assoc. Prof. Dianne Sika-Paotonu, University of Otago

A Pacific-led research team committed towards equity in heart health for Pacific communities, and through respectful collaborations, seeks to develop, and support co-designed Pacific solutions for



Pacific Peoples. This programme of work will have a specific focus on Rheumatic Heart Disease (RHD). The programme includes:

- **Pacific Research/Health Workforce Training**: Support and training for 30 Pacific heart health students/scholars, and scientists/clinicians/researchers in cultural safety, Pacific frameworks and methodological approaches, with a Pacific heart health conference planned
- Pacific Engagement & Codesign: Community engagement efforts through Pacific Fono and utilisation of Pacific approaches/frameworks, will enable Pacific communities living with RHD to share experiences and co-design solutions together
- **Pacific Scientific Projects**: Scientific projects will be presented to Pacific communities to consider as they co-design solutions for RHD.