

# Research Project Impact Case Study



Tāngata Whaikaha Māori Probabilistic Panel Survey Research

Rangahau Pae Uiui Tūpono mō Ngā Tāngata Whaikaha Māori

### **Short Research Title**

Te Ao Mārama: Māori Health, Wellbeing and Social Survey Panel

Te Ao Mārama: Pae Uiui mō te Hauora, Oranga me te Waiau Hapori o te Māori

### **Key researchers**

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# SSIF Areas of research impact | Ngā Wāhanga Pānga Rangahau SSIF

Please indicate with an X which statement in each row best describes your project.

Impact area	No impact expected	Future impact possible	On pathway for future impact	On pathway for actual impact achieved by end of project	Actual impact achieved
Value extraction from existing science			Х		
Improvements in public policy advice				Х	
Economic impact					
New/improved products and services			Х		
Reduced operating costs or commercial risk			Х		
New job opportunities.			Х		
Improved business and industrial processes		Х			
Environmental impact	•				
Reduced or mitigated environmental impact	Х				
Reduced or mitigated environmental risk	Х				
Improved condition of an environmental asset	Х				
Better understanding of the environment, and characterisation and management of natural capital		Х			
Health & Wellbeing impact					
Improved population health and health status for disadvantaged groups				Х	
Reduction in health maintenance costs			Х		
Early detection and mitigation of health risks				Х	
Improved wellbeing through development of human and social capital, and removal of institutional barriers				Х	
Social impact					
Increased knowledge and interest in science		Х			
Understanding of and resilience to real or perceived communal risk				Х	
Stronger social and infrastructure systems and improved techniques for delivery of public services				Х	
Vision Mātauranga	•			•	•
Indigenous innovation: economic growth through distinctive R&D.					Х
Taiao: Sustainability through iwi and hapu relationships with land and sea		Х			
Hauora/Oranga: improved health and social wellbeing				Х	
Mātauranga – explore indigenous knowledge for science and innovation					Х

## Introduction | Kupu Whakataki

### Why this work matters | Te hiranga o tēnei mahi:

For generations, tāngata whaikaha Māori have been missing from the datasets that drive Aotearoa's pandemic planning. Our kaupapa-driven, probabilistic panel study answers their call for visibility by putting disabled Māori knowledge, and tikanga whaikaha Māori principles, at the centre of infectious-disease research and response.

### What we are building? | Ngā mea kei te waihanga?:

Co-designed with community, the project is creating:

- Infrastructure for routinely gathering hauora and wellbeing data from tangata whaikaha Māori
- Equity-informed survey tools aligned to pandemic-resilience indicators
- A tāngata whaikaha Māori data-sovereignty framework
- Quantitative-analysis capability (mentorship, statistical training, clinical-translation planning)
- A leadership and succession pipeline for Māori and disabled researchers

### Long-term impacts | Ngā pānga pae tawhiti:

This mahi will:

- Embed mātauranga Māori in the design and delivery of quantitative infectious-disease research
- Empower tangata whaikaha Maori as active knowledge-holders guiding data use and interpretation
- Build national capability in panel methodology, data governance, and policy translation
- Inform clinical and public-health decision-making for future pandemic response

### What this will enable | Ka āhei tēnei ki:

- Equip government agencies and health providers with equity-sensitive evidence for disabled Māori
- Establish a scalable panel able to track health inequities over time and improve system preparedness
- Offer a national model for inclusive, ethical health research through the data-sovereignty framework

### Where this leads | Te aronga whakamua:

Together, these foundations convert an historical data gap into a living, community-owned evidence engine, capable of guiding real-time policy during future outbreaks and strengthening hauora outcomes every day in between. The next section, **Ngā Hua o Mōhoa Noa / Results to Date**, shows how much of that engine is already built.

### Results To-Date | Ngā Hua o Mōhoa Noa

Over the first 10 months (2 Sep 2024 – 30 Jun 2025) the project has moved from concept to an ethically-ready, community-endorsed research platform:

- **Co-design & engagement:** Ten regional wānanga, including hui with *Te Tira Tāngata Whaikaha Māori o Pōneke* and *Te Taumata Tāngata Whaikaha Māori o Aotearoa*, refined accessible formats, communication preferences and supported-decision-making tools for tāngata whaikaha Māori participation.
- Governance architecture: Panel Charter, Protocol, Data Management Plan, Privacy controls and a preliminary T\u00e4ngata Whaikaha M\u00e4ori Data Sovereignty Statement are completed and lodged with ethics.
- **Ethics milestones**: HDEC has granted *provisional* approval for Panel enrolment; the COVID-19 investigation application is finalised and will be submitted on receipt of full Panel approval.
- Survey & recruitment readiness: Panel Enrolment Questionnaire, advertising collateral and Compass NZ operational plan are finished. Recruitment will launch immediately after ethics sign-off, with an anticipated sample of n = 8,000 (exceeding the Te Nīwha target of 5,000)
- **Team capability**: A dedicated Research Coordinator (Dr Rachelle Martin, 0.137 FTE) has been appointed, relieving investigators of administrative load and improving continuity.
- **Community Capability & Capacity**: This critical element has been a primary focus to-date. Refer to the Project Impact Highlight Box below.

#### PROJECT IMPACT HIGHLIGHT: Community Capability & Capacity

The first phase of this project has focused on building relationships with diverse, priority communities so as to understand their specific needs. This will ensure that accessible formats and appropriate supports are in place to ensure the panel is responsive to the needs of Tangata Whaikaha Māori and their whānau.

Exploring accessible accommodations included understanding how to respond to the requirements of a range of Māori communities such as Tāngata Turi, Tāngata Kāpō and Māori with a range of learning disabilities.

Activation of these diverse Māori communities incorporates Mātauranga Māori from the lens of Māori with lived experience of disability. This includes weaving tikanga Māori into accessible approaches such as communication preferences, supported decision making and whānau resilience techniques.

This was an important step in the establishment of the panel as the voices and perspectives of Tāngata Whaikaha Māori and disaggregated data are typically missing in general surveys. Feedback received from these communities emphasised how valued they felt to be included in the early stages of designing accessible methods of collecting data. They highlighted how this empowered them to build their own research skills and Mātauranga Māori and contributed to increasing their willingness to participate in future surveys run via the panel.

## Impact | Pānga

### A. Pathway to Impact & Early Impacts | Ara Whai Pānga me Ngā Pānga Tuatahi

In the first ten months of this project our team have developed a range of early impacts:

### 1. Policy & System Influence

- Findings and community insights have already informed submissions to the Royal Commission of Inquiry into COVID-19 and the Waitangi Tribunal's WAI 2575 kaupapa.
- Expert evidence contributed to Whaikaha Ministry of Disabled People's draft National Disability
   Strategy 2025-30 and to Te Whatu Ora's prototype "disability alert" on the National Health Index.

### 2. Data Sovereignty Leadership

The bespoke Tāngata Whaikaha Māori Data Sovereignty Framework, now intellectual property vested in Te Ao Mārama Aotearoa Trust, offers a first-of-its-kind template for Indigenous-disabled data governance in Aotearoa. Sector stakeholders (i.e. Te Tāhū Hauora) are actively exploring adoption.

#### 3. Capability & Workforce Development

- **Māori research pipeline**: Mentorship in longitudinal panel methods, survey design and analytics is under way for Māori early-career researchers via iNZight Analytics Ltd training sessions.
- **Recognition**: PI A/Prof Tristram Ingham received the Companion of the King's Service Order (Apr 2025) for services to tangata whaikaha Maori, signalling peer esteem and appetite for project findings.

#### 4. Pandemic Preparedness

By embedding equity indicators and accessibility features into the survey modules, the project is creating a rapid-response evidence engine for future infectious-disease emergencies. Government agencies will have a standing panel able to generate real-time data on disabled Māori needs, dramatically shortening planning cycles.

#### B. Evidence of Progress toward SSIF Impact | Taunakitanga o te Kokenga ki Ngā Kāwai Pānga SSIF

The following are our teams assessed impact mechanisms:

SSIF category	Concrete evidence delivered to date
Public policy advice	Royal Commission briefings; Whaikaha strategy input; human-rights submissions.
Health & wellbeing	Culturally adapted enrolment tools and multimodal questionnaires ready for deployment, enabling the first dataset on COVID-19 outcomes and pandemic resilience among tāngata whaikaha Māori.
Vision Mātauranga – Hauora/Oranga	Māori-led data governance framework; 12+ regional wānanga building community research literacy
Social impact	Empowerment feedback from disability community participants reporting heightened confidence to engage in research and policy dialogues (qualitative wānanga findings)

### Te Niwha Research Project - Impact Case Study

### C. Next 12 Months | Ngā Marama 12 Kei Mua

As the team looks forward to the future outcomes and impacts to be derived from this research, we identify the following impact elements:

Quarter Key deliverable	Impact lens
Q3 2025 Ethics approval confirmed; launch recruitment campaign	Visible inclusion of tāngata whaikaha Māori imagery and Te Reo messaging to maximise reach
Q4 2025 Complete <b>Survey 1</b> (COVID-19 modules)	First national estimates of vaccination access, long-COVID prevalence and service gaps for disabled Māori
Q4 2025 Draft policy brief to Te Whatu Ora & Whaikaha	Embed findings into 2026 pandemic-preparedness funding round
Q1 2026 Data analysis & dissemination hui	Return of results to participants and co-development of intervention priorities with community

NB: Risk controls (stakeholder availability, investigator health, and administrative capacity) remain in force and have reduced all previously "High" risks to "Low–Medium" status

# Conclusion | Kupu Whakakapi

Looking ahead, the Tāngata Whaikaha Māori Wellbeing Panel is more than a dataset, it is a platform for *tino rangatiratanga* in infectious disease research, pandemic resilience and health. *Ko te pae tawhiti whāia kia tata, ko te pae tata whakamaua, kia tīna*: together we are bringing the distant horizon within reach and securing what we have gained, so that every future pandemic response is shaped by, for, and with disabled Māori.