Panel Research Protocol

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

Funder: Te Niwha

Sponsor: University of Otago, Wellington

Site: New Zealand

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1. INTRODUCTION

The **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel** is a groundbreaking initiative designed to address longstanding inequities in health, wellbeing, and social outcomes among Māori populations in Aotearoa New Zealand. This high-level protocol establishes the foundational governance, operational principles, and ethical frameworks required to create and sustain a longitudinal panel survey that will support multiple hypothesis-driven surveys over time.

1.1. Purpose of the Panel

The panel's primary purpose is to collect longitudinal data on health, wellbeing, social participation, and the social determinants of health among Māori adults, with a particular focus on tāngata whaikaha Māori (Māori with disabilities). By serving as a platform for diverse research projects, the panel will facilitate robust, culturally-informed insights that can inform evidence-based policymaking and intervention strategies.

1.2. Scope of the Protocol

This protocol governs the establishment, maintenance, and management of the panel, ensuring it remains aligned with its overarching purpose, population focus, and guiding values. While specific hypotheses and research objectives will be addressed in separate sub-protocols, this document provides the high-level framework to ensure consistency, sustainability, and cultural integrity across all panel-related activities. Subsequent future surveys will require their own separate ethical approval and data management processes.

1.3. Values and Guiding Principles

The panel positions itself from an holistic Te Ao Māori worldview, using methods grounded in kaupapa Māori methodologies, and underpinned by the principles of Māori data sovereignty, emphasizing:

- **Tika (Justice)**: Ensuring the panel is established and operated in a manner that delivers equitable outcomes for Māori communities.
- **Manaakitanga (Care and Respect)**: Prioritizing participant wellbeing and fostering trust through transparent and culturally appropriate practices.
- **Whanaungatanga (Relationships)**: Building and maintaining strong relationships with participants, stakeholders, and Māori communities.
- **Kotahitanga (Unity)**: Promoting collective action and shared purpose among researchers, participants, and communities.
- **Kaitiakitanga (Guardianship)**: Upholding Māori data sovereignty through robust governance and protection of participant data.

2. SCIENTIFIC RATIONALE

2.1. Strengthening Māori health, wellbeing and social survey infrastructure

Persistent inequities remain the signature of Aotearoa's official statistics. Māori life-expectancy still trails non-Māori by almost eight years, and the 2023/24 New Zealand Health Survey showed Māori adults were 70 percent more likely to describe their health as fair or poor than Pākehā. Māori rates of diabetes, smoking-related disease and severe psychological distress likewise exceed those of non-Māori, while imprisonment, crowded housing and household poverty also fall disproportionately on Māori whānau . The Waitangi Tribunal's *Hauora* report (WAI 2575) concluded that such disparities persist because Crown monitoring systems do not furnish governments with the timely, Māori-centred evidence needed to honour the active-protection and equity guarantees of Te Tiriti o Waitangi .

2.2. The limitations of current collections

Four national surveys dominate public reporting on Māori wellbeing.

- **The New Zealand Health Survey (NZHS)** interviews about 6 800 adults a year; only one adult in five identifies as Māori, giving roughly 1 300 Māori respondents. That is enough to estimate national prevalence but far too little for iwi-specific or age-by-gender analyses, and the cross-sectional design cannot follow individuals through policy or life-course transitions .
- **Te Kupenga**, Stats NZ's Māori post-censal survey, is rich in cultural content and interviews about 8 500 Māori once every five or six years . Yet the long interval means emerging issues—vaping, long-COVID, climate-driven displacement—remain invisible between waves, and the sample still fragments once it is sliced by rohe, age, or disability.
- **The General Social Survey (GSS)** fields about 8 000 adults biennially; Māori respondents typically number 1 200–1 300 (15 percent). The GSS provides broad social indicators but lacks kaupapa Māori constructs and, like NZHS, is purely cross-sectional .
- **The Integrated Data Infrastructure (IDI)** links administrative files for the whole population, but administrative systems collect little on lived experience, cultural identity, wairua or racism, and Māori governance of linkage and release processes remains incomplete .

Together these collections create a patchwork: points-in-time rather than trajectories; national averages rather than iwi- or hapū-level insight; and narrow biomedical or bureaucratic variables rather than holistic Māori conceptions of oranga.

2.3. Evidence for a future-facing Māori data system

Māori social-science methodologists have demonstrated how a probability-based, Māori-governed panel could fill these gaps. Greaves' feasibility study showed that the electoral roll offers a statistically robust sampling frame: a cohort of about 7 000 Māori adults would carry a design-based sampling error of roughly 0.6 percent while remaining representative by age, gender, region and deprivation . Sporle and colleagues have argued that when Māori control questionnaire content and data governance the resulting evidence enjoys greater accuracy, relevance and community trust—qualities essential for translating findings into effective policy.

A standing Māori probability panel would deliver three advantages unavailable in the present system. First, because the same whānau are re-contacted, analysts can trace causal pathways between

determinants such as housing or discrimination and subsequent health or employment outcomes; nothing comparable can be done with today's cross-sections. Second, weights and contact protocols are in place before crises strike, so rapid "pulse" modules can enter the field within days and inform emergency response, whether a pandemic wave, cyclone or cost-of-living shock. Third, governance arrangements anchored in Te Mana Raraunga principles ensure rangatiratanga over what is collected, how it is stored and who may use it, meeting both ethical obligations and practical needs for sustained Māori participation.

2.4. The imperative of powered disaggregation

An equally important gain is statistical power for small but high-priority populations. At present, national instruments cannot reliably illuminate whānau with intersecting vulnerabilities—rangatahi Māori excluded from school, Māori Rainbow communities, or iwi whose members number only a few thousand. The most acute gap concerns *tāngata whaikaha Māori* (Māori with lived experience of disability). During 2022, people receiving disability support were four times more likely to be hospitalised and thirteen times more likely to die with COVID-19; where ethnicity was recorded, Māori risk exceeded that of other groups, yet sample numbers were too thin to explain whether the excess reflected rural service gaps, inaccessible public-health messaging or systemic bias in care . A Māori probability panel sized for 7 000 participants would yield several hundred tāngata whaikaha Māori—enough to produce stable estimates and evaluate the impact of Pae Ora reforms or future pandemic protocols on this underserved group.

2.5. Conclusion

Persistent inequity, partial surveillance and the absence of Māori stewardship currently limit Aotearoa's evidence base for equitable policy. International and local scholarship demonstrates both the technical feasibility and the cultural legitimacy of a Māori-governed probability panel that can generate longitudinal, rapid, disaggregated insight. Such an infrastructure would convert Te Tiriti commitments from rhetoric into routine practice—furnishing government, iwi and community providers with the data power they need to design, target and evaluate interventions that honour Māori aspirations for tino rangatiratanga, hauora and collective flourishing.

3. PANEL OBJECTIVES

The **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel** is designed as a long-term, Māori and tāngata whaikaha Māori governed, resource to generate comprehensive, high-quality data that addresses critical knowledge gaps in Māori health, wellbeing, social participation, and social determinants of health. This section outlines the primary and secondary objectives that define the panel's purpose, guiding its establishment, maintenance, and ongoing use across multiple surveys.

3.1. Primary Objectives

The primary objectives of the panel are to:

3.1.1. Track Longitudinal Changes:

- Monitor health, wellbeing and societal participation outcomes among Māori adults over time, with a specific emphasis on tāngata whaikaha Māori.
- Identify trends and changes in key social determinants of health, including: housing, income, education, justice, and access to healthcare and welfare services.

3.1.2. Address Māori Health Inequities:

- Provide robust data to quantify intersectional health and wellbeing outcomes between and within Māori populations.
- Support the development of culturally responsive policies and interventions that improve health equity for Māori.

3.1.3. Uphold Kaupapa Māori Methodologies:

- Embed Māori values and principles into all aspects of the panel, ensuring that the research prioritises mana enhancing approaches, and both reflects and respects the lived experiences of Māori communities.
- Re-indigenise the system through a decolonizing lens to research that privileges Māori perspectives and narratives.

3.1.4. Promote Māori Data Sovereignty and Governance:

- Ensure Māori control and governance over their data through the role of TAMA as data kaitiaki.
- Align data management practices with Te Mana Raraunga principles to uphold the rights of Māori communities to determine how their data is used and shared.

3.2. Secondary Objectives

The panel will support a broad range of secondary objectives, enabling its use across diverse research studies while maintaining consistency with its overarching purpose:

3.2.1. Platform for Future surveys:

- Provide a foundation for hypothesis-driven future surveys that explore specific research questions related to Māori health and wellbeing.
- Enable agile responses to emerging health crises, such as pandemics or environmental disasters, by leveraging existing panel structures for rapid data collection.

3.2.2. Support Evidence-Based Policy:

- Generate actionable insights that inform health, social, and disability policies, ensuring they are grounded in robust, culturally aligned evidence.
- Provide data that supports public sector accountability and improved service delivery for Māori communities.

3.2.3. Empower Māori Voices in Research:

- Create opportunities for participants to contribute their narratives and perspectives, ensuring their experiences inform future health and social policies.
- Facilitate consultation and collaboration with iwi, hapū, and whānau to reflect the diverse realities of Māori communities.

3.2.4. Develop Longitudinal Research Capacity:

- Establish a scalable and sustainable panel structure that can accommodate new research priorities over time.
- Build capacity and capability among Māori, rangatahi, tāngata Whaikaha Māori, researchers and organizations to develop their skills to conduct longitudinal studies that reflect Māori priorities and aspirations.

3.3. Alignment with Broader Goals

The panel aligns with the following broader goals, ensuring its relevance and value across research, policy, and community contexts:

3.3.1. Enhancing Public Health:

- Contribute to the improvement of Māori health and wellbeing by providing data that highlights areas of need and opportunity for intervention.
- Support initiatives that address the determinants of health, creating a foundation for healthier, more equitable futures for Māori communities.

3.3.2. Enabling Cultural Resilience:

- Strengthen Māori cultural resilience by embedding indigenous knowledge systems into the research process.
- Promote narratives of strength, identity, and self-determination through data that reflects Māori aspirations and values.

3.3.3. Facilitating Cross-Sector Collaboration:

- Serve as a resource for collaborative research across communities, whānau/hapū/Iwi, health, education, social services, and environmental sectors.
- Foster partnerships between Māori organizations, academic institutions, and policymakers to drive meaningful change.

3.3.4. Developing Critical Research Infrastructure:

- Establish and sustain research infrastructure tailored to the needs and priorities of tāngata whaikaha Māori.
- Create a platform that supports ongoing research into disability and health inequities, enabling a deeper understanding of the systemic barriers faced by tāngata whaikaha Māori.

3.3.5. Building Research Capability and Accountability:

- Enhance the research and analytic skills of tāngata whaikaha Māori to foster greater rangatiratanga (self-determination) in the research domain.
- Strengthen the ability of tāngata whaikaha Māori to hold institutions, including the Crown, accountable for health, social, and disability outcomes, ensuring equity and justice.

4. PANEL GOVERNANCE

The governance of the **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey** Panel is designed to ensure robust oversight, cultural safety, and alignment with Māori values and aspirations. This section outlines the structures, roles, and responsibilities that will guide the establishment, maintenance, and operation of the panel.

4.1. Governance Structure

The governance structure comprises key entities and roles responsible for managing the panel, upholding its purpose, and ensuring its alignment with kaupapa Māori principles:

4.1.1. Project Sponsor:

- The University of Otago Wellington serves as the project sponsor, providing oversight and ensuring adherence to funding requirements and ethical standards. The University of Otago Research team is Māori led and consists predominantly of Māori researchers. This Māori team has considerable expertise in developing, conducting and disseminating national surveys incorporating te ao Māori principles.

4.1.2. Contract Research Organizations (CROs):

- **University of Auckland**: Leads the technical aspects of data collection, management, and analysis, with a focus on rigorous survey methodology.
- **iNZight Analytics Ltd**: This Māori led organisation, which incorporates kaupapa Māori principles, will provide statistical and analytical expertise to ensure high-quality data interpretation and reporting.
- **Te Ao Mārama Aotearoa Trust (TAMA)**: This Māori trust will act as the data kaitiaki, ensuring that the governance of Māori data aligns with tikanga Māori and reflects the aspirations of tāngata whaikaha Māori.

4.1.3. Advisory Committees:

- **Cultural Advisory Group**: This Māori group of experts will provide guidance to ensure that all panel activities are culturally appropriate and respectful of Māori values.
- **Scientific Advisory Board**: Offers expertise in survey design, data analysis, and longitudinal research, ensuring the scientific rigor of the panel's operations. This group will consist of Māori and international indigenous researchers with panel expertise.

4.2. Roles and Responsibilities

Governance and operational entities will perform the following key functions to ensure the panel operates effectively and aligns with its values:

4.2.1. Project Governance Board:

- Oversee the panel's operations, ensuring it remains aligned with its purpose, objectives and values.

- Approve budgets, timelines, and strategic decisions related to panel activities.

4.2.2. Project Lead

- Ensure the project is on track for timely completion of deliverables
- Ensure all activities comply with ethical standards, including obtaining HDEC approvals and adhering to the Privacy Act 2020.
- Monitor adherence to consent protocols and participant rights.

4.2.3. TAMA as Data Kaitiaki:

- Uphold Māori data sovereignty principles, ensuring that data is collected, stored, and used in ways that benefit Māori communities.
- Provide oversight on data access and use, ensuring alignment with Te Mana Raraunga principles.

4.2.4. Operational Teams:

- Responsible for day-to-day activities, including recruitment, data collection, and participant engagement.
- Coordinate between CROs and other stakeholders to ensure smooth operation.

4.3. Māori Governance and Kaitiakitanga

Māori governance is central to the panel's structure, reflecting the principles of **tino rangatiratanga (self-determination)** and **kaitiakitanga (guardianship)**:

4.3.1. Role of TAMA:

- As the kaitiaki of tāngata whaikaha Māori data, TAMA will ensure that all data is managed with cultural integrity and respect for tikanga Māori.
- Actively involve Māori communities in decision-making processes, ensuring their voices guide the panel's direction.

4.3.2. Cultural Integrity:

- All panel activities will adhere to kaupapa Māori methodologies, emphasizing whanaungatanga (relationships), manaakitanga (care), and kotahitanga (unity).
- Governance structures will include Māori leadership at all levels, ensuring that decisions reflect Māori aspirations.

4.4. Decision-Making Processes

Decision-making within the governance structure will be collaborative, transparent, and inclusive, with mechanisms in place to resolve conflicts and ensure accountability:

4.4.1. Consensus-Based Decision-Making:

- Major decisions will be made through consensus among governance entities, ensuring alignment with the panel's purpose and values.

4.4.2. Escalation Pathways:

- Disputes or unresolved issues will be escalated to the Project Governance Board for resolution.

4.4.3. Regular Reviews:

- Governance processes will undergo periodic reviews to ensure they remain effective, culturally aligned, and responsive to emerging needs.

4.5. Accountability and Reporting

4.5.1. Reporting Framework:

- Governance entities will report on their activities and decisions to stakeholders, including funding agencies, Māori communities, and research collaborators.
- Reports will include updates on panel progress, recruitment outcomes, and participant feedback.

4.5.2. Transparency:

- Ensure transparency in all governance activities by sharing decisions, policies, and protocols with stakeholders through appropriate communication channels, including the Te Ao Mārama website.

5. PANEL ESTABLISHMENT

The establishment of the **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey** Panel involves the systematic recruitment of participants and the development of foundational processes to ensure the panel's representativeness, cultural integrity, and long-term sustainability. This section outlines the target population, recruitment strategies, and key processes for the panel's formation.

5.1. Target Population

The target population for the panel includes:

5.1.1. Adults of Māori Descent:

- Individuals aged 18+ who self-identify as being of Māori descent, reflecting the diversity of Māori communities across Aotearoa New Zealand.

5.1.2. Tāngata Whaikaha Māori:

- A specific focus on Māori individuals with lived experiences of disability, ensuring their inclusion and representation within the panel.

5.1.3. Geographic and Demographic Representation:

- Participants will be recruited from urban, rural, and remote regions to ensure geographic diversity.
- Stratification will be applied to reflect demographic factors such as age, gender, and socio-economic status.

5.2. Recruitment Strategy

Recruitment will follow a phased, probabilistic approach to ensure a representative sample of Māori adults while meeting specific inclusion criteria:

5.2.1. Initial Cohort Recruitment:

- Participants from the original **Te Ao Mārama study** (approx.7,000) will form the foundation of the panel. This group has previously engaged with kaupapa Māori research and will be invited to join the panel through follow-up communication.
- Informed consent will be obtained for participation in the longitudinal panel.

5.2.2. Augmentation Through Electoral Roll Sampling:

- Probabilistic (random) sampling from those who have identified as being of Māori descent on both the Māori and General electoral rolls will be used to augment the initial cohort. This approach ensures representativeness and aligns with the legal requirements of the **Electoral Act 1993**.
- Names and addresses from the electoral rolls will be used to mail an invitation.
- Supplementary electoral roll data (such as occupation) will be de-identified and stored separately, with unique identifiers assigned to maintain participant confidentiality.

5.3. Recruitment Inclusion and Exclusion Criteria

5.3.1. Inclusion Criteria:

- Self-identification as being of Māori descent.
- Aged 18 years or older.
- Consent to participate in the longitudinal panel.

5.3.2. Exclusion Criteria:

- Inability to provide informed consent.
- Non-Māori descent individuals.

5.4. Data Collection Processes During Establishment

5.4.1. Data Sources:

- Initial data collection will include demographic, screening and engagement preference questions.

5.4.2. Modes of Data Collection:

- Multi-modal approaches will be employed to maximize accessibility and participation, including:
  - **Online Surveys**: Self-administered surveys for participants with digital access.
  - **Phone Interviews**: Conducted by trained interviewers for participants who prefer or require assistance.
  - **Postal Surveys**: Available for participants without access to digital platforms.

5.4.3. Participant Onboarding:

- Participants will receive clear information about the panel's purpose, their role, and their rights, including the ability to opt out at any time.

5.5. Establishment Milestones

Key milestones for panel establishment include:

5.5.1. Completion of Initial Recruitment:

- Engaging participants from the original Te Ao Mārama study and obtaining their consent for panel participation.

5.5.2. Augmentation from the Electoral Roll:

- Conducting the first wave of probabilistic sampling to complete panel recruitment.

5.5.3. Baseline Data Collection:

- Gathering initial data to establish comprehensive participant profiles and identify key health and wellbeing indicators.

5.6. Ethical and Cultural Considerations

5.6.1. Cultural Safety:

- All recruitment activities will align with kaupapa Māori principles, ensuring that participants are treated with respect and their cultural identity is valued.

5.6.2. Informed Consent:

- Consent processes will be transparent, with participants fully informed about their rights, including data usage and withdrawal options.

5.6.3. Māori Data Sovereignty:

- Data collection and storage will adhere to Te Mana Raraunga principles, with TAMA overseeing data governance as kaitiaki.

6. PANEL MAINTENANCE

Maintaining the **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey** Panel requires robust strategies to ensure ongoing participant engagement, data quality, and representativeness over time. This section outlines the processes for panel replenishment, participant retention, and operational protocols designed to sustain the panel's long-term utility.

6.1. Replenishment Strategy

To maintain the panel's representativeness and accommodate participant attrition, regular replenishment will be conducted using a systematic, probabilistic approach:

6.1.1. Annual Replenishment:

- New participants will be recruited annually through probabilistic sampling from the Māori electoral roll.
- This replenishment ensures that the panel remains representative of Māori adults, including tāngata whaikaha Māori, as the population evolves.

6.1.2. Targeted Replenishment:

- If specific subgroups (e.g., rural Māori, older adults, tāngata whaikaha Māori) are underrepresented, focused recruitment efforts, will be implemented to restore representativeness.

6.1.3. Retention of Core Participants:

- While replenishment addresses attrition, efforts will prioritize retaining core participants to strengthen longitudinal data continuity.

6.2. Participant Retention

Retention strategies will focus on building trust, providing value to participants, and fostering a sense of community and purpose within the panel:

6.2.1. Regular Communication:

- Participants will receive updates through newsletters, emails, or phone calls, keeping them informed about the panel's progress and findings.
- Culturally appropriate messaging will ensure that communication aligns with Māori values and practices.

6.2.2. Participant Incentives:

- Enrolment to panel will not incentivised; however subsequent surveys may be.
- If subsequent data collection is to be incentivised this will be addressed in the individual survey documentation.
- Koha (gifts) or small incentives may be provided by surveys to recognise participants' time and contributions. This may include entry into draws for prizes.

- If subsequent data collection is to be incentivised, this will be addressed in the individual survey documentation.
- Non-monetary incentives, such as access to lay summaries and opportunities to engage with research findings, will also be offered.

6.2.3. Community Engagement:

- Regular community events, such as hui (gatherings) and webinars, will provide opportunities for participants to connect with the research team and other panel members.

6.2.4. Responsive Participant Support:

- A dedicated team member will be available to address participant queries, manage consent updates, and support ongoing engagement.

6.3. Opt-Out Procedures

Participants will have the right to withdraw from the panel at any time. Clear and respectful opt-out procedures will be implemented to balance participant autonomy with data integrity:

6.3.1. Withdrawal Options:

- Participants may choose to: a) Retain all previously provided data within the panel. b) Remove access to any unpublished data provided within the last four weeks (acknowledging practical limitations on removing analyzed or published data).

6.3.2. Confirmation of Withdrawal:

- Participants will receive confirmation of their withdrawal, along with assurances about how their data will be managed.

6.3.3. Exit Surveys:

- Optional exit surveys will be offered to understand reasons for withdrawal and identify potential improvements to panel management.

6.4. Data Quality Assurance

To maintain the integrity of panel data over time, rigorous quality assurance protocols will be implemented:

6.4.1. Regular Data Audits:

- Data will be reviewed periodically to identify and address inconsistencies or gaps.

6.4.2. Participant Follow-Up:

- Regular follow-ups will be conducted to verify and update participant information, ensuring data accuracy.

6.4.3. Methodological Consistency:

- Data collection methods and survey instruments will be reviewed and standardized to ensure comparability across waves.

6.5. Ethical and Cultural Considerations

6.5.1. Participant Wellbeing:

- The wellbeing of participants will remain a priority, with all interactions conducted in a manner that upholds manaakitanga (care) and respects participant preferences.

6.5.2. Cultural Alignment:

- Maintenance activities will reflect kaupapa Māori values, fostering whanaungatanga (relationships) and kotahitanga (unity).

6.5.3. Transparency and Trust:

- Participants will have access to clear information about how their data is used and how the panel contributes to broader research and policy outcomes.

6.6. Evaluation of Maintenance Strategies

To ensure the effectiveness of maintenance protocols, regular evaluations will be conducted:

6.6.1. Participant Satisfaction:

- Surveys and feedback mechanisms will assess participant satisfaction with panel processes and engagement.

6.6.2. Retention Metrics:

- Metrics such as retention rates, replenishment success, and representation balance will be reviewed to guide improvements.

6.6.3. Continuous Improvement:

- Findings from evaluations will inform updates to retention strategies and panel management practices.

7. DATA MANAGEMENT AND SOVEREIGNTY

The **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel** upholds the principles of Māori data sovereignty, ensuring that data governance reflects the rights, values, and aspirations of Māori communities. This section outlines the framework for data collection, storage, access, and use, with a focus on protecting participant privacy, maintaining data quality, and embedding cultural integrity.

7.1. Data Collection

7.1.1. Ethical approval

- All specific scientific investigations (future surveys) conducted via the panel will require separate ethical approval.
- These ethical applications will be made as separate individual HDEC or IEC submissions.

7.1.2. Data Sources:

- Data will be collected via:
  - Web-based surveys.
  - Phone interviews conducted by trained personnel.
  - Postal surveys for participants without digital access.

7.1.3. Types of Data Collected:

- Demographic information (age, gender, location, iwi affiliation).
- Health and wellbeing indicators (e.g., chronic conditions, mental health status).
- Social determinants of health (e.g., housing, income, education).
- Disability-related experiences for tāngata whaikaha Māori.

7.2. Consent for Data Use:

- Explicit informed consent will be obtained for:
  - Participation in the panel.
  - Use of data for specific studies.
  - Linking data to previous Te Ao Mārama datasets where applicable.

7.3. Data Storage

7.3.1. Secure Infrastructure:

- Data will be stored on encrypted, password-protected servers located at the University of Auckland, New Zealand to ensure local jurisdiction over participant information.

7.3.2. Separation of Identifiable Data:

- Identifiable data (e.g., names, contact details) will be stored in a separate, unlinked database accessible only to a designated team member responsible for participant contact and koha management.

7.3.3. De-identified Data:

- All analytical data will be de-identified, with unique participant codes replacing personal identifiers.

7.3.4. Retention Periods:

- Data will be retained following the conclusion of each data collection cycle for 10 years, or as required by current ethical and legal standards.

7.4. Data Access and Use

7.4.1. Access Control:

- Access to identifiable data will be restricted to designated personnel.
- De-identified data may be made accessible to approved research teams for specific studies that have been approved by the governance board and have ethical approval.

7.4.2. Use of Data:

- Data will be used for:
  - Longitudinal analysis of health and social trends.
  - Hypothesis-driven future surveys that align with the panel's purpose.
- No external linking to datasets (e.g., Integrated Data Infrastructure) will occur without explicit consent from participants.

7.4.3. Transparency in Use:

- Participants will receive regular updates on how their data is being used and the outcomes it informs.

7.5. Māori Data Sovereignty Framework

7.5.1. Guiding Principles:

- The panel adheres to the principles of Te Mana Raraunga, ensuring Māori control over data governance, access, and use.
- TAMA will act as the kaitiaki (guardian) of Māori and tāngata whaikaha Māori data, ensuring alignment with tikanga Māori.

7.5.2. Māori Data Sovereignty Framework:

- A Māori data sovereignty framework will guide all panel activities, emphasizing:
  - **Rangatiratanga**: Self-determination over data governance.
  - **Whakapapa**: Acknowledging the interconnectedness of data with Māori identity and relationships.
  - **Manaakitanga**: Ensuring data is used to uplift and benefit Māori communities.

- Governance and oversight is by a panel of members drawn from TAMA, the cultural advisory group and the scientific advisory board who will agree on their Terms of reference in conjunction with the University of Otago research team.

7.5.3. Commitment to Tāngata Whaikaha Māori:

- An ancillary focus will prioritize the specific needs of tāngata whaikaha Māori within the overarching framework, addressing their unique experiences and aspirations.

7.6. Privacy and Confidentiality

7.6.1. Participant Rights:

- Participants retain the right to access, correct, or withdraw their data, as outlined in the opt-out procedures (Section 5.3).

7.6.2. Mitigating Privacy Risks:

- Regular audits will ensure compliance with the Privacy Act 2020 and HISO 10029:2015 Health Information Security Framework.
- Breaches will be promptly reported to participants, the HDEC, and the Privacy Commissioner, as required.

7.7. Data Quality Assurance

7.7.1. Validation Processes:

- Data will be reviewed for completeness and accuracy, with checks to identify and resolve inconsistencies.

7.7.2. Standardized Protocols:

- Collection methods and analytical approaches will follow standardized protocols to ensure consistency across waves.

7.7.3. Continuous Improvement:

- Feedback from participants and researchers will inform ongoing enhancements to data management practices.

7.8. Ethical and Legal Compliance

7.8.1. HDEC Oversight:

- All data-related activities will comply with HDEC requirements and relevant ethical standards.

7.8.2. Legal Frameworks:

- The panel's data management aligns with the Privacy Act 2020 and Health Information Privacy Code 1994.

8. PANEL OPERATIONS AND OVERSIGHT

The operational management and oversight of the **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel** are critical to ensuring its long-term success and alignment with its purpose. This section outlines the operational structures, processes, and oversight mechanisms necessary to sustain the panel and its activities.

8.1. Operational Framework

The panel will operate under a structured framework to ensure efficiency, cultural integrity, and adherence to ethical standards:

8.1.1. Project Management:

- A dedicated project management team will oversee daily operations, including recruitment, data collection, and participant engagement.
- The team will ensure coordination across Contract Research Organizations (CROs) and other stakeholders.

8.1.2. Standard Operating Procedures (SOPs):

- SOPs will govern all operational activities, including recruitment, data collection, data storage, and participant communication.
- These procedures will be reviewed periodically to ensure they remain relevant and effective.

8.1.3. Key Roles:

- **Coordinating Investigator**: Provides overall leadership and ensures alignment with project goals and ethical requirements.
- **Operational Team Leads**: Manage specific functions such as data collection, participant engagement, and communications.
- **Cultural Advisors**: Ensure all operations adhere to kaupapa Māori principles and respect cultural values.

8.2. Oversight Mechanisms

Robust oversight mechanisms will ensure that the panel operates with transparency, accountability, and responsiveness:

8.2.1. Governance Board:

- The Project Governance Board will provide strategic oversight, approving major decisions and monitoring progress against project milestones.

8.2.2. Regular Reporting:

- The operational team will provide regular updates to the Governance Board, including recruitment progress, data collection outcomes, and participant feedback.

8.2.3. External Reviews:

- Periodic external reviews will assess the panel's performance, ensuring it continues to meet its objectives and ethical obligations.

8.2.4. Continuous Monitoring:

- Key performance indicators (KPIs) such as recruitment rates, retention metrics, and data quality will be monitored regularly to identify and address any issues.

8.3. Panel-access fees and cost-recovery model

8.3.1. The Te Ao Mārama Panel is a public-good, Māori-led research asset. Fees are not-for-profit and exist solely to (a) keep the sample robust and culturally safe, (b) provide koha/honoraria for participants, and (c) cover the direct costs of survey delivery and data stewardship .

8.3.2. Guiding principles

- Public-good priority – Only studies with demonstrable public-benefit aims will be considered; commercial market-research is excluded.
- Cost-recovery, not revenue-generation – Fees are calibrated to recover real operating costs and will be set to break even over a rolling three-year horizon.
- Equity & tikanga – The model supports koha for all panel members and sustains culturally grounded engagement practices (manaakitanga, whanaungatanga).
- Transparency & accountability – The Governance Board approves the schedule annually and publishes it on the panel website together with a plain language explanation.

8.3.3. Standard fee schedule *(effective 1 July 2025)*

Tier	Eligible clients	Survey length (instrument minutes)	Base fee (ex GST)	Additional question fee (per item)	Notes
A Kāwanatanga	Ministries, DHBs, Crown entities	≤5 min	NZ $10 000	NZ $120	Includes sample of up to 1 000; weighting file supplied
B Kaupapa Māori / iwi / NGO / university	Māori organisations, iwi authorities, NGOs, tertiary researchers	≤5 min	NZ $8 000	NZ $90	20 % discount applied automatically
C Student / early-career	Post-grad or ECR projects endorsed by a university ethics committee	≤5 min	NZ $5 000	NZ $70	Capped at 20 items; mentorship provided

Add 30 % for instruments 11–15 minutes; studies beyond 15 minutes require bespoke costing. Oversampling of specific sub-groups (e.g., tāngata whaikaha Māori) attracts a marginal cost of NZ $0.80 per additional sampled participant.

8.3.4. Fee waivers, reductions & kaupapa Māori support

- Full waiver may be granted where the Governance Board determines exceptional collective benefit (e.g., urgent public-health surveillance).
- Sliding-scale reductions (up to 50 %) are available for unfunded Māori community-initiated projects.
- All discounts are conditional on meaningful Māori partnership (e.g., co-design, shared governance).

8.3.5. Invoicing & payment terms

- An itemised quotation is issued after protocol approval; 50 % is invoiced on booking, 50 % on delivery of cleaned data.
- Payments are due within 30 days. Delayed payment may result in suspension of data release.

8.3.6. Periodic review and adjustment

- The Governance Board will review fee levels, cost assumptions, and discount policies at least annually or earlier if material cost changes occur. Any revisions will be communicated via the panel website and will not apply retrospectively to already-approved projects.

8.4. Participant Communication

Effective communication with participants is essential for maintaining trust and engagement:

8.4.1. Regular Updates:

- Participants will receive regular updates about panel activities, including recruitment progress, key findings, and upcoming research opportunities.

8.4.2. Participant Support:

- A dedicated support team will address participant inquiries, manage consent updates, and provide assistance as needed.

8.4.3. Feedback Mechanisms:

- Participants will have opportunities to provide feedback on their experiences, ensuring that their voices inform the panel's operations.

8.5. Risk Management

Risk management processes will be implemented to address potential challenges in panel operations:

8.5.1. Identifying Risks:

- Risks such as recruitment challenges, participant attrition, and data security breaches will be identified and assessed.

8.5.2. Mitigation Strategies:

- Mitigation plans will include enhanced recruitment efforts, retention strategies, and robust data security protocols.

8.5.3. Contingency Planning:

- Contingency plans will be in place to address unexpected challenges, ensuring continuity of panel operations.

8.6. Technology and Systems

Technology will play a key role in supporting panel operations and ensuring efficiency:

8.6.1. Participant Management System:

- A secure, centralized system will track participant information, manage consent records, and support communication efforts.

8.6.2. Data Collection Platforms:

- Secure and user-friendly platforms will facilitate data collection, offering multiple modes to accommodate participant preferences.

8.6.3. Performance Dashboards:

- Dashboards will provide real-time insights into panel metrics, enabling timely decision-making and adjustments.

8.7. Cultural Oversight

Cultural oversight will ensure that all operational activities reflect Māori values and respect tikanga:

8.7.1. Cultural Advisory Group:

- This group will provide ongoing input on operational practices, ensuring alignment with kaupapa Māori methodologies.

8.7.2. Engagement with Māori Communities:

- Regular engagement with iwi, hapū, and whānau will ensure the panel remains connected to the communities it serves.

8.7.3. Cultural Training:

- Operational staff will receive training in Māori cultural practices and values to ensure culturally safe interactions with participants.

8.8. Evaluation and Improvement

Regular evaluation processes will support continuous improvement in panel operations:

8.8.1. Operational Audits:

- Internal audits will assess compliance with SOPs and identify opportunities for improvement.

8.8.2. Participant Satisfaction Surveys:

- Surveys will capture participants' perspectives on panel activities, informing refinements to operational practices.

8.8.3. Annual Review:

- An annual review of panel operations will assess progress against objectives and inform strategic planning for the coming year.

9. Participant Feedback and Reporting

Participant feedback and effective reporting are integral to the success and sustainability of the **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel**. Transparent, culturally aligned communication ensures participants feel valued and informed about how their contributions shape research and policy. This section outlines the mechanisms for engaging participants, providing feedback, and reporting research outcomes.

9.1. Participant Feedback

9.1.1. Regular Communication:

- Participants will receive regular updates about the panel's progress, key findings, and how their data contributes to improving Māori health and wellbeing.
- Updates will be provided through culturally appropriate channels, including newsletters, email communications, and hui (community gatherings).

9.1.2. Feedback Mechanisms:

- Participants will have opportunities to share their experiences and perspectives through:
  - Periodic satisfaction surveys.
  - Dedicated feedback forms accessible via the Te Ao Mārama website.
  - Direct communication with the participant support team.

9.1.3. Incorporating Feedback:

- Feedback will inform continuous improvement in panel operations, ensuring that participant experiences and needs are addressed promptly.

9.2. Reporting Framework

9.2.1. Lay Summaries:

- Accessible summaries of key findings will be published on the **Te Ao Mārama website** (www.teaomarama.maori.nz) to ensure transparency and inclusivity.
- Summaries will include visuals, infographics, and plain-language narratives to enhance understanding.

9.2.2. Interactive Reporting:

- The website will feature interactive tools to allow participants to explore data trends and insights in an engaging and meaningful way.

9.2.3. Culturally Aligned Outputs:

- Reports will incorporate Māori values, using language, design, and narratives that resonate with participants and their communities.

9.3. Community and Stakeholder Reporting

9.3.1. Engaging Māori Communities:

- Regular hui (meetings) will be held to present findings to Māori communities, providing opportunities for discussion and feedback.
- Reports will be shared with iwi, hapū, and whānau, reinforcing the panel's commitment to accountability and inclusivity.

9.3.2. Policy and Stakeholder Briefings:

- Findings relevant to public health and social policy will be communicated to key stakeholders, including government agencies, NGOs, and health providers, through tailored reports and presentations.

9.3.3. Research Dissemination:

- Results will be shared with the broader research community through academic publications, conference presentations, and collaborative projects.

9.4. Commitment to Transparency

9.4.1. Accessible Information:

- Participants will have access to all publicly available outputs, ensuring they are informed about the panel's impact and outcomes.

9.4.2. Updates on future surveys:

- Participants will be notified of new future surveys, with clear explanations of how their data may contribute and the potential benefits of participation.

9.4.3. Acknowledging Contributions:

- Reports and publications will acknowledge the contributions of participants and the role of Māori communities in shaping the research.

9.5. Ethical and Cultural Considerations

9.5.1. Respect for Participant Privacy:

- All feedback and reporting mechanisms will ensure participant confidentiality, adhering to data protection standards.

9.5.2. Cultural Relevance:

- Outputs will reflect kaupapa Māori principles, ensuring that reporting is meaningful, respectful, and empowering for Māori communities.

9.5.3. Participant Choice:

- Participants will have the option to engage with feedback and reporting materials at their discretion, respecting individual preferences.

9.6. Monitoring and Evaluation of Feedback Processes

9.6.1. Feedback Effectiveness:

- Regular evaluations will assess the effectiveness of communication and feedback mechanisms, ensuring they meet participant needs.

9.6.2. Continuous Improvement:

- Insights from evaluations will guide refinements to reporting strategies and participant engagement processes.

10. STUDY TIMELINE AND MILESTONES

The timeline for the **Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel** is structured to ensure that the panel is fully established and the first sub-study (separate ethics application) initiated by **November 2025**.

10.1. Key Phases

The following high-level phases guide the establishment and operation of the panel:

10.1.1. Preparatory Phase (Now – June 2025):

- Secure ethics approval and electoral roll data access.
- Finalize recruitment materials and survey instruments.
- Begin engagement with stakeholders and Māori communities.

10.1.2. Recruitment and Establishment Phase (July– August 2025):

- Recruit the initial cohort from Te Ao Mārama participants.
- Augment the panel using probabilistic sampling from the Māori electoral roll.
- Conduct baseline data collection for all recruited participants.

10.2. Milestones

2025

- **November 2024 to June 2025**:
  - Finalize overarching protocol and sub-study-specific protocols.
  - Submit applications for HDEC approval and electoral roll data access.
  - Develop and test recruitment materials and survey instruments.
  - Begin preparatory community engagement activities, including hui (meetings) with key stakeholders.
  - Recruitment of Te Ao Mārama participants begins.
  - Engagement with tāngata whaikaha Māori to ensure culturally aligned recruitment.
- **August 2025**:
  - Complete initial cohort recruitment (Te Ao Mārama participants).
  - Begin augmentation of the panel using electoral roll data.
  - Complete panel augmentation.
  - Conduct baseline data collection for all participants.
  - Begin implementation of the first sub-study

10.3. Dependencies and Contingencies

10.3.1. Ethics Approval and Data Access:

- Timely approval from the HDEC and access to the electoral roll are critical. Contingencies include alternative recruitment strategies if delays occur.

10.3.2. Participant Recruitment:

- Recruitment timelines will account for potential challenges in reaching underrepresented groups, with targeted strategies to address gaps.

10.3.3. Survey Completion:

- The timeline allows flexibility to accommodate unforeseen delays in data collection or analysis.

10.4. Monitoring and Reporting

10.4.1. Progress Reviews:

- Monthly reviews will ensure activities are on track and address any delays promptly.

10.4.2. Community Engagement:

- Regular hui with Māori communities will provide updates on progress and gather feedback.

10.4.3. Final Reporting:

- Findings from the first sub-study will be disseminated via the Te Ao Mārama website and community presentations.