DATA MANAGEMENT PLAN

Version: 2.0

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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

Co-ordinating Investigator: Tristram Ingham

CONTENTS

1 INTRODUCTION

This Data Management Plan outlines how data will be handled during the study, **'Te Ao Mārama: Māori Health, Wellbeing, and Social Probabilistic Survey Panel'** (the Study), and following its completion.

This data management plan relates to the establishment, maintenance, and management of the panel, ensuring it remains aligned with its overarching purpose, population focus, and guiding values. This document provides the high-level framework to ensure consistency, sustainability, and cultural integrity across all panel-related activities.

Specific research activities and data management plans for future studies using the panel will be addressed in separate protocols, ethics applications and data management plans.

2 STUDY STRUCTURE

The Sponsor will enlist the support of the named Contributing Research Organisations (CRO) to co-ordinate the Study. The Sponsor is responsible for supervising any and all outsourced activities.

TABLE 1. STUDY STRUCTURE

Sponsor	University of Otago (Wellington), PO Box 7343, Wellington South, Wellington 6242.
Contributing Research Organisations (CRO)	Centre of Methods and Policy Application in the Social Sciences (COMPASS), The University of Auckland, Private Bag 92019, Auckland 1142. iNZight Analytics Ltd, Auckland, New Zealand Unit 1102, 5 Hohipere Street, Eden Terrace, Auckland 1010, New Zealand Te Ao Mārama Aotearoa Trust Suite 12063, Level 1, 6 Johnsonville Road, Johnsonville, Wellington 6037
Lead Site (New Zealand)	University of Otago (Wellington), PO Box 7343, Wellington South, Wellington 6242.
Co-ordinating Investigator	A/Prof Dr Tristram Ingham ONZM, Department of Medicine, University of Otago (Wellington), PO Box 7343, Wellington South, Wellington 6242.
Imaging Vendor	Not Applicable.

3 ORGANISATIONAL DATA GOVERNANCE OVERSIGHT

The Study will comply with relevant data legislation, regulations, and codes. These include The Privacy Act 2020 and The Health Information Privacy Code 1994, The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, HISO 10029:2015 Health Information Security Framework, HISO 10064:2017 Health Information Governance Guidelines, and Digital and Data Technology Services (2020).

Additionally, the following institutional data policies pertaining to the Sponsor and each Contributing Research Organisation (CRO) apply for the Study.

University of Otago:

https://www.otago.ac.nz/staff/policies/key-policies-for-groups/key-policies-for-research-staff

- Intellectual Property Rights Policy
- Institutional Research Repository Policy
- Research Consultation with Māori Policy
- Responsible Practice in Research – Code of Conduct
- Guidelines for ethical practices in research and teaching involving human participants

University of Auckland:

- Te Mana Rāraunga Māori Data Sovereignty Network
- Privacy Framework (https://www.auckland.ac.nz/en/privacy.html)
- Research Code of Conduct (https://cdn.auckland.ac.nz/assets/central/about/the-university/how-the-university-works/policy-and-administration/code-of-conduct-research.pdf)
- The Health Research Council's Guidelines for Researchers on Health Research involving Māori (https://www.hrc.govt.nz/resources/guidelines-researchers-health-research-involving-maori)

iNZight Analytics Ltd:

- Te Mana Rāraunga Māori Data Sovereignty Network

Te Ao Mārama Aotearoa Trust:

- Te Ao Mārama Aotearoa Trust Deed
- Whāia Te Ao Mārama

4 CONSENT FOR DATA COLLECTION AND USE

All participants will be informed of, and provide consent for, the collection and use of their data for the purposes of this study, and for any mandatory secondary uses.

5 DATA COLLECTION

Data will be collected from the following sources:

- Web-based survey questionnaire from consenting participants.
- Direct communication with the consenting participant if participant indicates their preference is for survey-based phone interview with an interviewer. This option has been included in the invitation letter for the survey.

Data will be collected primarily by the Investigator or designated study staff. All study personnel involved in data collection will be trained in study protocol, and collection requirements.

Collection of data will be limited to that necessary for the specified purposes of the study, or for additional purposes that the participant has explicitly consented to.

6 PRIVACY AND CONFIDENTIALITY

Participants' privacy and confidentiality will be respected through the protection of their data as outlined in this plan. The Investigator will comply with legal and regulatory requirements regarding the privacy and confidentiality of participants' data.

6.1 BREACH OF PRIVACY / CONFIDENTIALITY

A breach of privacy means unauthorised or accidental access to, or disclosure, alteration, loss, or destruction of a participant's information.

In the event participant privacy and confidentiality is breached during the study, the following steps will be taken:

- Action will be taken to reduce the risk of harm following the breach. Where possible, the recipient will be contacted and asked to destroy or return any electronic the disclosed material.
- The participant will be informed of the breach as soon as practicable or notification would be likely to prejudice the health of the participant (after consultation with the participant's health practitioner, where practicable), and provided with support as required.
- The CRO and/or Sponsor will conduct a quality review to ascertain factors contributing to the breach and any corrective action required to prevent future breaches.
- The approving HDEC will be informed.
- For notifiable privacy breaches of privacy under the Privacy Act 2020, the New Zealand Privacy Commissioner will be notified in accordance with that Act.

7 FORMS OF DATA

7.1 IDENTIFIABLE DATA

Personally identifiable information in the Study involves: information from the publicly available Māori and General electoral roll records; name and contact phone number of consenting participants who indicate their preference is for survey-based phone interview with an interviewer; and, email addresses or mobile/phone numbers of consenting participants (who provide an email address to receive a lay summary of the Study results, and/or email address or mobile/phone number for the purposes of entering the Study prize draw).

Personally identifiable information in the Study will only be available to the Investigator and CRO, and will be stored securely and separately from participant data. Any personally identifiable information will not be linked in any way to data collected for study purposes.

7.2 DE-IDENTIFIED DATA

De-identified data will be collected using unique participant codes as identifiers.

Any personally identifiable information will not be linked in any way to data collected for study purposes.

Participants will be informed that de-identified data may be accessed, corrected, or withdrawn up to one month after data collection. A lay summary of the Study results will be available to the participants should they wish (consenting participants will provide their email address in order to receive a copy).

7.3 ANONYMOUS / ANONYMISED DATA

Not applicable.

8 ACCESS TO AND USE OF DATA

Collected data will be used to answer the research questions and fulfil the study requirements described in the study protocol, and for the secondary purposes outlined in Sections 7.4 and 7.5.

8.1 IDENTIFIABLE DATA

Identifiable data may be accessed by the following groups:

- The Investigator and the CRO, to fulfil protocol requirements, for example, follow-up with consenting participants who provide their email address to receive a lay summary of the Study results.

8.2 DE-IDENTIFIED DATA

De-identified data may be accessed and used by the groups described in Section 8.1.

De-identified data may also be made available to other researchers, as described in Section 8.5.

8.3 Anonymous/Anonymised Data

Not applicable.

8.4 Sending of Data Overseas

Not Applicable.

8.5 Future Use of Data

Future use of data will be dealt with via each sub-study submitting an ethics application clarifying the position on future use of data.

For the purposes of the panel, future use of de-identified data will be limited to:

- Unspecified purposes which are directly related to the study question(s).
- Unspecified purposes which are related to the item and/or condition under study.

8.6 Commercial Use of Data

Not Applicable.

8.7 Data Linking

At this stage, the panel does not intend to enable data linking by default. Should data linking be proposed as part of a future survey, explicit consent will be obtained from panellists before any such activity. Additionally, separate ethical approval will be sought for the specific data involved in the proposed linkage.

8.8 Databank / Registry

Not Applicable.

9 STORAGE AND DESTRUCTION OF DATA

9.1 Identifiable Data and Source Documents

Identifiable data will be stored on encrypted, password-protected servers located in New Zealand (University of Auckland Research Drive; https://research-hub.auckland.ac.nz/managing-research-data/research-data-storage/research-drive) to ensure local jurisdiction over participant information. All electronic files will be deleted from the servers after 10 years.

Access to identifiable data will be restricted to a defined list of panel staff for the purposes of maintaining contact with panellists. No panel clients or other panel researchers will have access to identifiable data.

9.2 De-identified Data

De-identified data will be stored on encrypted, password-protected servers located in New Zealand (University of Auckland Research Drive; https://research-hub.auckland.ac.nz/managing-research-data/research-data-storage/research-drive) to ensure local jurisdiction over participant information. All electronic files will be deleted from the servers after 10 years.

10 Consultation

The Study was fully peer reviewed by Te Niwha Grant Assessing Committee. The co-design protocol subsequently underwent peer review by two independent senior academics. We also consulted with Te Ao Mārama Aotearoa (TAMA).

10.1 Māori Data Sovereignty

Data will be collected from participants identifying as Māori. Personal and health information is a tāonga (treasure) and will be treated accordingly. The research team takes data storage and protection seriously. We are guided by Te Mana Raraunga Principles for Māori Data Sovereignty (Te Mana Raraunga 2018).[1] In particular, any electronic raw data will be stored on local servers with local jurisdiction.

11 Return of Results

As data has been anonymised, participants are unable to receive results of their individual survey responses. A lay summary of the Study results will be available to the participants should they wish (consenting participants will provide their email address in order to receive a copy).

11.1 Incidental Findings

Not Applicable.

11.2 Results Arising from Future Research

11.2.1 Data

No future unspecified research is planned for data collected in this study.

11.2.2 Databank / Registry

Not Applicable.

[1] Te Mana Raraunga (2016). Māori Data Sovereignty Network Charter. https://static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5913020d15cf7dde1df34482/1494417935052/Te+Mana+Raraunga+Charter+%28Final+%26+Approved%29.pdf

12 WITHDRAWAL OF DATA

Participants may withdraw consent for the collection of data at any time, without providing a reason.

Should a participant withdraw consent, no further data will be collected by study staff. Participants may ask for their data to be withdrawn up to one month after data collection.