

The Māori Health Data Governance Model: A planning and protocol checklist



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Abstract

Purpose Māori health data (MHD) governance is a critical enabler of achieving health equity for Māori. The Māori Data Governance Model (the Model) provides a framework for all stages of Māori data handling but has yet to be meaningfully implemented within health settings. This study aimed to meet the need for health-specific guidance by adapting the Model to create an MHD governance checklist. This checklist can be used by health researchers and agencies to develop and embed their own MHD governance protocol (e.g. embed within study protocol).

Methods Eight *Pou* were adapted from the Model and further questions were generated from The Health Services and Outcomes Kaupapa Inquiry WAI2575, National Ethics Advisory Committee guideline and the CARE (collective benefit, authority to control, responsibility, ethics) principles.

Main findings Every effort should be made to include Māori participation in the health research or agency that involves any aspect of MHD within all adapted eight data *Pou*. If this is not possible, an explanation for reasons why and actions for contributing to short-term and long-term solutions for this should be provided.

Principal conclusion The MHD governance planning and protocol checklist provides a *te Tiriti o Waitangi* approach for health researchers and agencies that can be implemented alongside current ethical practices. The checklist is an actionable tool that can be used to contribute to health equity for Māori.

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Highlights

- Health researchers and agencies need to create Māori data governance planning and protocol documentation.
- Adaptation of the Māori Data Governance Model for a health setting provides a meaningful implementation of all stages of Māori health data handling.
- Using this Māori health data governance planning and protocol checklist will contribute to health equity for Māori.

Introduction

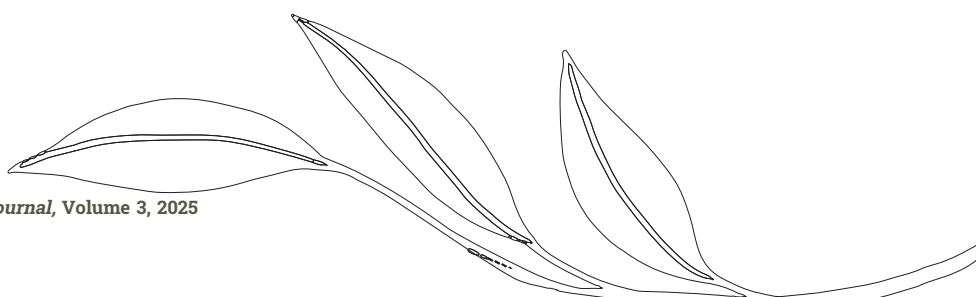
Māori in Aotearoa New Zealand have experienced poorer health outcomes than non-Māori for more than a century, across most (if not all) standard measures of population health (Sheridan et al. 2024; Waitangi Tribunal 2019). Given the systematic and preventable nature of health inequities, it is important to identify opportunities where targeted health services and/or research can effect change, as well as mechanisms to detect and potentially upscale successes within the health system, and to monitor for *te Tiriti o Waitangi* breaches (Walker et al. 2017). For Māori, data are a *taonga* and a strategic resource for advancing collective wellbeing and self-determination (Ruckstuhl 2021). In health settings, Māori health data (MHD) governance is recognised as a critical enabler of achieving health equity for Māori.

Māori data governance (MDG) relates to who has authority and power over the following: research design; how data are collected and analysed; what data are reported and how data are reported; and who has access to and can use the data (Lovett et al. 2019). Māori data sovereignty (MDSov) is distinct from MDG – it refers to the inherent rights of Māori to control data derived from and pertaining to them, their knowledge systems, customs or territories (see: the Māori data sovereignty principles, *Te Mana Raraunga* 2018).

Sovereignty thus establishes the principle and right, while governance provides the practical framework for implementing those rights. The Māori Data Governance Model (the Model) provides a framework for all stages of Māori data handling (Kukutai et al. 2023a). It was developed by experts in MDG to be used by Māori and non-Māori working in all agencies (e.g. government organisations, researchers), with the intention that it could be used to assist those agencies to meet data governance needs of Māori and as a mechanism for Māori to exercise authority over decision-making relating to Māori data (Kukutai et al. 2023a). Importantly, it was published by *Te Kāhui Raraunga*, an independent trust established to action the priorities of the Data Iwi Leaders Group of the National Iwi (tribal) Chairs Forum.

The creation of the Model was *te Tiriti o Waitangi* led, under the vision *Tuia te korowai o Hine-Raraunga* (data for self-determination), and connected by desired outcomes aligned with the five priority domains of the National Iwi Chairs Forum (Kukutai et al. 2023a).

The Model is *te Tiriti o Waitangi* led, with specific alignment with *Tino rangatiratanga* (Article 2), ensuring that Māori maintain self-determination, autonomy, power and control over *taonga*, or for the purposes of this research activity, data (Came et al.





2020; Kukutai et al. 2023b; Riley 2023). One key finding from the Waitangi Tribunal WAI2575 Health Services and Outcomes Kaupapa Inquiry claim stated that to ensure health equity for Māori and non-racist experiences within the health system, *Tino rangatiratanga* needs to be expressed from development, implementation and evaluation (Came et al. 2020). Contemporary collective expressions of *Tino rangatiratanga* are also the foundation of *Matike Mai Aotearoa* (the Independent Working Group on Constitutional Transformation), which centralises the importance of *He Whakaputanga o te Rangatiratanga o Nu Tirenī* (The Declaration of Independence of New Zealand) and *te Tiriti o Waitangi* (Matike Mai Aotearoa 2025). Therefore, there is multiple documentation supporting the need to plan for and enact MDG.

These sentiments are also reflected in the United Nations Declaration on the Rights of Indigenous Peoples, specifically Article 31, which states that Indigenous peoples ‘...have the right to maintain, control, protect, and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions’ (United Nations 2007). Additionally, reports by the United Nations Special Rapporteur on the Right to Privacy on big and open data and the use of personal health data unambiguously assert the need for governments and corporations to uphold Indigenous data sovereignty (Special Rapporteur on the Right to Privacy 2018, 2019). This is further supported by the Council for International Organisations of Medical Sciences’ international guidelines on human health research, which recommend health research alignment and adherence to principles of ethical conduct to ensure that health research is beneficial and, at the very least, minimises the potential for harm to occur because of health research activities (Council for International Organisations of Medical Sciences

(CIOMS) 2016; Special Rapporteur on the Right to Privacy 2018).

Within Aotearoa New Zealand, ethical guidelines that include MDSov include *Te Ara Tika* (Guidelines for Māori research ethics: A framework for research and ethics committee members) and The National Ethical Standards for Health and Disability Research and Quality Improvement (Hudson et al. 2019; National Ethics Advisory Committee 2019). An example of MDSov within these guidelines is that Māori should be involved in all aspects of the research from design, collection, analysis, interpretation and data management (Hudson et al. 2019; National Ethics Advisory Committee 2019). Globally, there is increasing recognition by non-Indigenous agencies that Indigenous data governance standards should be applied to Indigenous health data, underscoring the timeliness and relevance of the Special Rapporteur on the Right to Privacy reports (Engstrom et al. 2024; United Nations 2021). This global message highlights the need; what is needed now is implementation.

In the New Zealand Medical Journal, leading health researchers outlined recommendations on addressing responsiveness to Māori through excellent health research to ‘build towards equity and in doing so ensure that no one is left behind’, highlighting the importance of considering in-built systemic and structural errors that can occur when interpreting Māori data obtained from multiple datasets (Reid et al. 2017).

The Health Research Council of New Zealand invests approximately \$NZ126 million per year in health research, resulting in over 370 funded research projects in an 8-year period (2006–14) (Showell et al. 2023). Considering the volume of research being carried out in Aotearoa there is likely to be a high





demand by health researchers for support to develop MDG planning and protocol documentation (e.g. reporting back to funders, ethics application, quality improvement activities), and to build capability of the researchers and agencies to operationalise MDG.

In Aotearoa, current best practice is to use the National Ethical Standards for Health and Disability Research and Quality Improvement (written by the National Ethics Advisor Committee [the NEAC guideline]) for general ethical guidance and the Health and Disability Ethics Committee Data Management Plan templates regarding data handling, the Model for MDG, and checklists such as the CONSIDER statement (CONSIDER) for strengthening reporting of health research involving Indigenous peoples (Huria et al. 2019; Kukutai et al. 2023a; Moher et al. 2010; National Ethics Advisory Committee 2019).

In the Model's current form, all aspects of Māori data usage are included and, although thorough, they are high level (as noted in the report itself), so there is a need for health-specific examples and guidance on how the guidance and expectations in the Model would be implemented, addressing the policy implementation gap. This study aimed to meet the need for health-specific guidance by adapting the Model to create an MHD governance checklist that health researchers and agencies can use to develop and embed their own MHD governance protocol (e.g. embed within study protocol or project plan). This supports the impact of MDG and adds to the sparse literature outlining how MDG can contribute to improving health outcomes for *whānau*, for example in supporting vaccination approaches in the COVID-19 pandemic and bowel screening in Aotearoa (McLeod et al. 2021; Sterling et al. 2024).

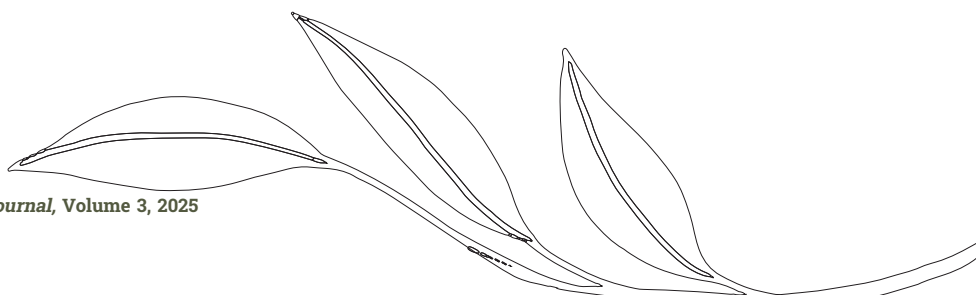
Before further outlining the health-specific MDG, a definition of Māori data adapted from the Model for a health setting is provided: Māori data are information and/or knowledge, digital or digitisable, that is collected, for example: health outcomes, experiences of a health service, data on social determinants of health, traditional Māori health practices and knowledge (Kukutai et al. 2023a). This study focused on MHD governance relating to all health data collected from individuals and collectives, including that sourced directly (e.g. surveys, focus groups, community *hui*, clinical trials) or from administrative datasets (e.g. health service data, population data, health outcome measures and digital data).

Methods

The vision and goals of the Model were upheld during the adaption process: *Tuia te korowai o Hine-Raraunga* (data for self-determination), to enable 'iwi, hapū, and Māori organisations, businesses and communities to pursue their own goals for cultural, social, economic, and environmental wellbeing and to address inequities' (Kukutai et al. 2023a). The Model includes eight *Pou* (pillars); (1) Data capacities and workforce development; (2) Data infrastructure; (3) Data collection; (4) Data protection; (5) Data access and sharing; (6) Data use and reuse; (7) Data quality and system integrity; and (8) Data classification (Figure 1). Each *Pou* contains a set of priorities, key actions and guiding questions.

Adaption of the Model for project planning and documentation checklist for MHD governance

The adaption process of the Model began by one researcher (LK) reviewing the eight data *Pou* and creating a checklist for the key priorities within a health setting. The eight *Pou*, priorities and key actions were retained during the adaption process.



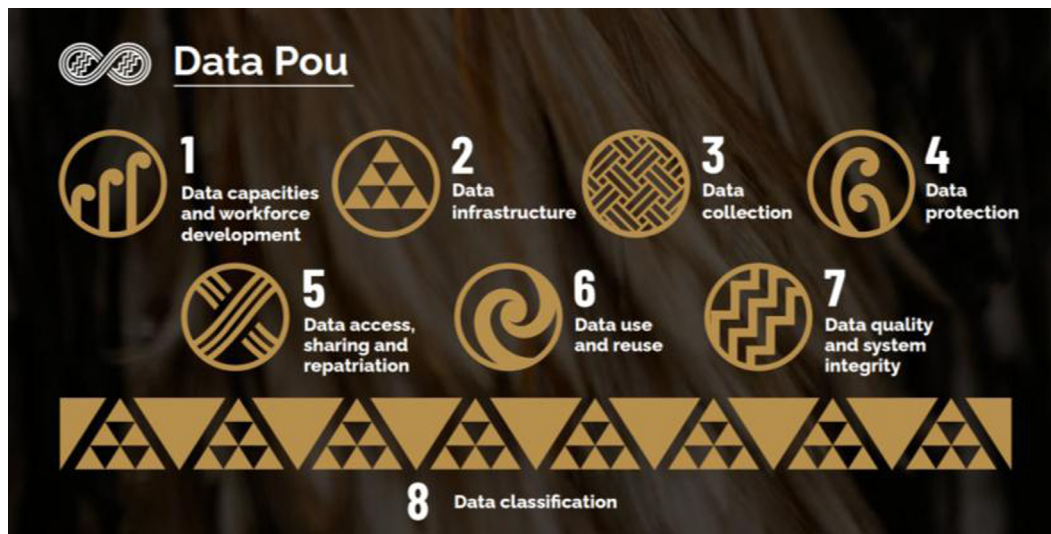


Figure 1: From page vii Māori Data Governance Model Data *Pou*. Used with the permission of Data Iwi Leaders Group and *Te Kāhui Raraunga*.

Questions for evidence

Example questions for the eight data *Pou* within the Model were created for health researcher and agency contexts. If questions within the Model were to be included, questions were adapted for a health context and categorised under each original title of the eight data *Pou* within the Model. Three additional resources that are health specific to Aotearoa and/or include Indigenous data governance principles were all cross referenced for question generation. These resources were: the Health Services and Outcomes Kaupapa Inquiry WAI2575 (Clark 2019), NEAC guidelines (Hudson et al. 2019; National Ethics Advisory Committee 2019), and the CARE principles (collective benefit, authority to control, responsibility, ethics) (Jennings et al. 2023). Question generation from these three sources were used to test and improve the applicability across health and research settings.

In application of the proposed implementation framework outlined below, researchers were required to also obtain appropriate ethical approval

(e.g. *iwi*, university, national). Where these approvals were not required, NEAC, *Te Ara Tika* and ethical data handling principles were applicable (Hudson et al. 2019; National Ethics Advisory Committee 2019).

The first iteration of the questions was presented to the research team, who were experts in either MDG development and tool testing and/or researchers in Māori health or health equity (Māori and non-Māori). The research team provided feedback on the guideline questions for appropriateness of the questions to use in a health setting, and these suggestions were incorporated into a revised version. A second iteration was presented, and further refinements were made. Questions were reviewed if applicable for those in an agency or at an individual level and categorised as yes for applicable, or optional if not essential.

Results

An MHD governance planning and documentation checklist was created using the eight data *Pou* headings and eleven subheadings from the Model



Item	Checklist item
Pou 1: Data capacities and workforce development	
1.	Describe how anti-racist practices will be implemented
2.	Specify how the project will grow Māori data capabilities and support the growth and capability of Māori health workforce development when using MHD
Pou 2: Data infrastructure	
3.	Describe how data infrastructure is decentralised, distributed, sustainable, secure and future focused
Pou 3: Data collection	
4.	Describe how Māori health needs will be prioritised when deciding what data to collect
Pou 4: Data protection	
5.	Describe how MHD will be protected through all parts of the data handling process
Pou 5: Data access and sharing	
6.	Describe how MHD will contribute to achieving health equity for Māori and/or for Māori to have a good experience within the health system
Pou 6: Data use and reuse	
7.	Describe how MHD use and reuse will contribute to achieving health equity for Māori
8.	Describe how MHD use and reuse occurs in a way that meets Māori-led aspirations for health
Pou 7: Data quality and system integrity	
9.	Identify a chief MHD steward
10.	Describe how ethnicity data are collected and analysed, and any limitations of these data
Pou 8: Data classification	
11.	Describe how MHD coding will occur using categories that are Māori led

Table 1: Project planning and documentation checklist for Māori health data (MHD) governance

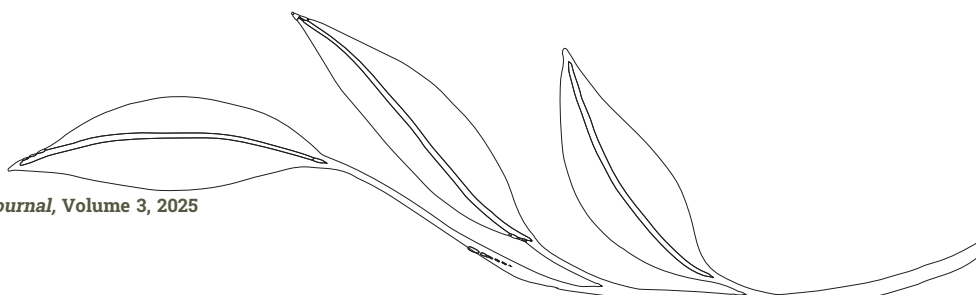
(Table 1). To elaborate on each of the data *Pou*, there are supporting explanations of each *Pou* heading and subheading. The questions and prompts within each data *Pou* subheading are to be used to guide planning and implementation documentation. Not all prompts will be applicable to every situation; however, if some are partially met, a description of capacity building should be provided. For people completing the checklist, if an entire data *Pou* is not included because it is deemed to be irrelevant, there should be justification provided for the exclusion. There may be items within the data *Pou* that have different considerations at organisational, service or research project levels; therefore, an explanation of this should be included, for example: some groups may not be able to involve a chief MHD steward if the people they approach are overcommitted.

Every effort should be made to include Māori participation in the health research or agency that is

involved in any aspect of MHD and in designing health equity for Māori research; if not possible, an explanation for reasons why and actions for contributing to short-term and long-term solutions for this should be given.

Pou 1: Data capacities and workforce development

Pou 1 emphasises the importance of implementing anti-racist practices and investing in Māori leadership and expertise. It is important to ensure that access to MHD is not restricted by research organisations or agencies. Where MHD is made available, potential risks associated with these data, such as the use of deficit-based interpretation and analyses, must be considered and mitigated. To ensure that anti-racist practices are implemented, MHD interpretation and analysis must take a pro-equity approach, uphold Māori cultural values, make privilege explicit, not blame Māori for health inequities, and use MHD for collective benefit and the improvement of Māori health and wellbeing. The following are prompts for





data capacities and workforce development and are not exhaustive:

1. Staff will ensure that MHD is used to centre *iwi/hapū/whānau*-led solutions.
2. From the MHD, staff will identify who is experiencing privilege within the health system.
3. If MHD is aggregated, it is analysed through the lens of *Te Ao Māori*.
4. If MHD is aggregated, it is done in a way that does not stigmatise Māori.
5. When data sets are large enough to prevent identification of participants, de-identified MHD will be made available (e.g. open access journals, *hui* (meet) with Māori stakeholder groups and participants).
6. The research team or agencies assess the level of experience with MHD governance (e.g. new, proficient, expert) and ensure that there is sufficient level of experience within the group to ensure that MHD is interpreted in a culturally safe way for Māori, and in ways that are consistent with all ethical approvals and processes.
7. The health research team or agencies have the support of *tikanga* (customs) expertise and/or *kaumātua* (Elder) support for MHD governance.
8. The health research team or agencies will aim to develop and/or use MHD classification and analysis frameworks (e.g. Health Information Standards Organisation (HISO) Ethnicity Data Protocols).

Data Pou 2: Data infrastructure

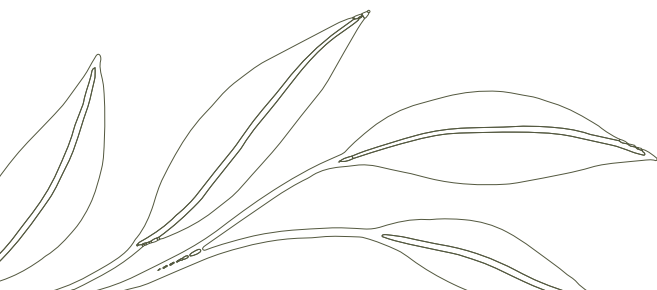
Data *Pou* 2 is about how data infrastructure needs to work for Māori, is decentralised, distributed, sustainable, secure and future focused. The following are prompts for data infrastructure and workforce development and are not exhaustive:

1. MHD is stored in Aotearoa by an Aotearoa-owned business consistent with MDSov requirements.
2. For MHD that has an *iwi, hapū* and/or *whānau* right or interest, these groups have had their preferences for data storage established (e.g. in their own data warehouses and cloud services).
3. The data infrastructure is sustainable to ensure that future generations of Māori can access and use the de-identified MHD.
4. Only necessary MHD will be collected and therefore stored.
5. MHD will be securely stored in an environmentally sustainable way (e.g. institutional sustainability office reports on carbon emissions associated with data storage and/or software use).

Data Pou 3: Data collection

Data *Pou* 3 is about prioritising MHD needs, collecting only what is needed and how data are collected. Collected data should be treated as *taonga* (precious) and by association are *tapu* (sacred, restricted). Everyone involved in collecting MHD is responsible for ensuring that the *taonga* is cared for and looked after (Beaton et al. 2017), and because of this responsibility, appointing an MHD steward should be considered. An MHD steward's role could be, and not limited to, ensuring the eight data *Pou* are implemented, and that the knowledge gained through data acquisition benefits Māori. It is not current routine practice to appoint an MHD steward and the health system and researchers may need to develop capacity and capability, and identify roles and responsibilities, to deliver on the role of the MHD steward that is linked to funding and full-time equivalent time.

Māori participants need to experience *Kia tau te wairua o te tangata*; this loosely translates to the level of cultural safety and cultural comfort that *iwi, hapū, whānau* and individuals have, in this case, when





sharing their health data (Beaton et al. 2017). Cultural safety occurs once both the individual and the organisation/systemic processes are critically examined for power, privilege and bias (Curtis et al. 2019). Operationalising this approach to cultural safety is a way for researchers and agencies to contribute to achieving equitable health outcomes.

Where research groups or agencies wish to engage with *iwi*, *hapu*, *whānau* and *hāpori* (community), first consider pre-existing relationships with Māori within the organisation and Memorandum of Understanding agreements to prevent inundating Māori communities with requests for engagement.

There are also requirements, according to the NEAC, that state participants have the right to free, prior and informed consent and have the ability to reduce, withdraw and re-consent; and health researchers or agencies should continue to follow these rights as they are not duplicated in the list below (National Ethics Advisory Committee 2019). The following are prompts for data collection and are not exhaustive:

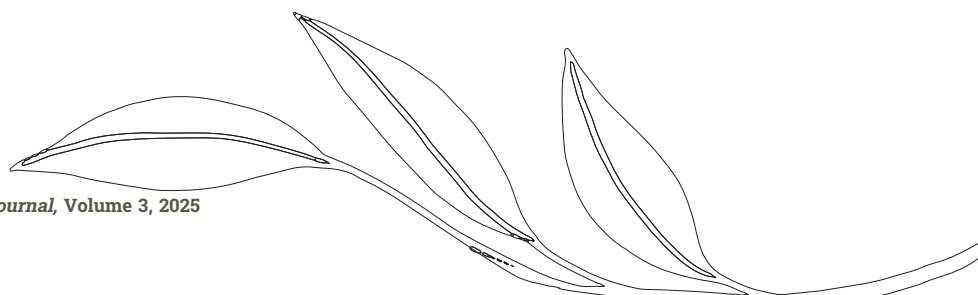
1. Collected MHD will be of mutual benefit, ethical consent driven, inclusive and relevant to the needs of *iwi*, *hapū* and *whānau*.
2. Prior to MHD collection, an explanation and demonstration of how the research outcome(s) is of value and may benefit the participant, *whānau*, *hapū* and *iwi*.
3. Engage with *iwi*, *hapu* and *whānau* to ensure that the research activity is going to contribute to addressing their health priorities.
4. The outputs and impacts from the MHD collection are likely to contribute to health equity for Māori.
5. In general, and where possible, research should support *iwi*, *hapū* and *whānau*-led initiatives with the intention of a long-term reciprocal relationship.

6. The research group and/or agencies plan to monitor MHD collection practices.
7. To facilitate data for self-determination, MHD will be collected using categories that are Māori led and, where able, engage with *iwi* and/or *hapū* if data collection from these groups would be beneficial.
8. If other sources of similar MHD are available, review if it is necessary to collect more MHD.
9. The consent to participate in health research occurs in a way that upholds the *tikanga* and *mana* (status) of each participant and the collective.

Data Pou 4: Data protection

As described in *Pou 3*, MHD is considered to be a *taonga* and needs to be protected by those who are involved with any part of the data handling. Data *Pou 4* describes approaches that can be taken to ensure that MHD is collected, de-identified, stored and has access limitations implemented to ensure only essential access. All aspects of data handling will meet legislative requirements in accordance with the Privacy Act 2020; these requirements have not been included in the list below. The following are prompts for data protection and are not exhaustive:

1. In most situations, MHD will be deidentified, and all processes will be put in place to ensure that MHD is not easily re-identified. There may be circumstances where re-identification is needed (e.g. for health benefit, quality improvement). Where re-identification is needed, robust processes are in place and well described.
2. It is known if MHD is stored onshore or offshore and the implications of this on future access for *iwi*, *hapū* and *whānau*.
3. Researchers will disclose any financial gain from health research activity/activities.
4. Any financial gains from health research will be disclosed with *iwi/hapū/whānau* and, where





possible, how financial gains can be shared with *iwi/hapū/whānau* will be investigated.

Pou 5: Data access and sharing

The goal for collecting MHD is for the data to contribute to achieving health equity for Māori, and for improved Māori experience within the health system. Therefore, within this data *Pou*, a description is required for how collected data could contribute to health equity. Consultation and collaboration with *iwi/hapū/whānau* Māori health researchers will be an important activity to meet the requirements of this *Pou*. The NEAC standard activities, for example providing participant information leaflets, have not been included in this checklist. The following are prompts for data access and sharing and are not exhaustive:

1. Collected MHD will contribute to achieving health equity for Māori and contribute to enabling good experiences for Māori within the health system.
2. MHD will be used for direct, tangible and meaningful Māori health benefit(s).
3. Māori are collaborating author(s) to support, participate and approve manuscripts for publication.
4. Consider generating resources to include *te reo* Māori and affirm *Te Ao* Māori.
5. MHD will be findable, accessible, interoperable and reusable.
6. Māori research consultation occurs to identify the potential for community harm from the perspective of Māori (e.g. *Ngāi Tahu* Research Consultation Committee at *Ōtākou Whakaihū Waka* (University of Otago).

Pou 6: Data use and reuse

Like previous *Pou*, the use and reuse of MHD needs to occur in a way that is going to make a positive contribution to achieving health equity and in a way

that meets Māori-led aspirations of *hauora* (health and wellbeing). If health equity is not planned for, inequities can be built into the system; therefore, research into and/or implementation of new tools or interventions must consider the potential impacts of these on health equity to avoid introducing biases inherent within these tools or interventions. For example, as pre-existing algorithms may have inbuilt biases, processes must be put in place to ensure that the potential for algorithmic bias is considered and pre-empted. Similarly, when data are being used for secondary analyses or for the development of health prediction models, these data should be examined for inherent biases. Any development of artificial intelligence needs to be culturally appropriate for Māori; therefore, *Te Ao* Māori needs to be included (Whittaker et al. 2023). To ensure that this worldview is included, Māori developers/clinicians/communities/patients and their *whānau* should be included in all aspects of decision-making processes (Whittaker et al. 2023).

All aspects of data use and reuse of human tissues will meet legislative requirements in accordance with the Human Tissue Act 2008; these requirements have not been included in the list below (New Zealand Ministry of Health 2008). The following are prompts for data use and reuse and are not an exhaustive list:

1. The use and reuse of MHD will be performed in a way that is meaningful and makes a positive contribution to Māori aspirations of health and wellbeing.
2. There is a documented process for how participants will consent to be part of the research. Participants need to be informed of the purpose of the research project and associated data collection and use (e.g. research, quality improvement). Consider a collective consent process for *whānau* Māori.
3. A Māori worldview, for example through *tikanga* and *mātauranga* (knowledge), has been applied if





artificial intelligence, algorithms and/or risk prediction tools are used or developed.

4. If using pre-existing algorithms, evaluation for bias has been undertaken prior to use to ensure that racist algorithms are not used.
5. A Māori lens is applied to existing MHD that are being used for secondary analyses.
6. Where algorithms are used, the research team is transparent about how decisions are made, what the data inputs are, and the MHD needs to be readily findable and communicated in clear language that a layperson can understand.

Pou 7: Data quality and system integrity

Data quality and system integrity is about putting into place standards, auditing, monitoring and compliance processes. Monitoring, for example, should identify and document individual and collective forms of ‘data harm’. All research activities should collect ethnicity data and do so under the HISO Health Standards for Ethnicity Data (Ministry of Health 2017a). There are known issues with ethnicity data quality, including misclassification and numerator and denominator bias (Cormack and McLeod, 2010; Harris et al. 2022). When using secondary data sets, misclassification of ethnicity may be built into the dataset, leading to perpetuating errors when the data are analysed. In their research outputs, users of secondary data should discuss the quality of ethnicity data, including the likely impact of issues with ethnicity data quality on their findings. Additionally, to maintain all aspects of data security, at least one member of the team needs to have overall responsibility as the named MHD steward. The following are prompts for data quality and system integrity and are not exhaustive:

1. Ethnicity data are collected and analysed according to the ethnicity data standards for the health sector.

2. For new data, MHD will be evaluated for accuracy and quality (e.g. if using data not collected within the standards, then evaluate ethnicity data for quality, and report on the limitations of ethnicity data). If data are not collected under the HISO standards, consider re-collection and/or state limitations of the data (Ministry of Health 2017b).
3. For secondary data, evaluate ethnicity data for quality, and report on the limitations of the ethnicity data.

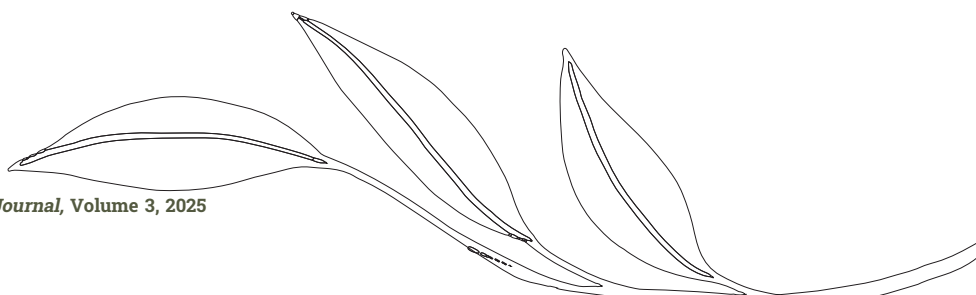
Pou 8: Data classification

Data classification is primarily about the use of Māori ontologies and *tikanga* (cultural values and protocols) to identify and describe data provenance, data characteristics, legal and extra-legal forms of ownership and rights. In accordance with HISO, Māori have the right and the opportunity to ensure that their identity is recorded in a way that they choose and that they have an opportunity to have it corrected. Like mentioned in data Pou 3, to facilitate data for self-determination, MHD will be coded using categories that are Māori led. The following are prompts for data classification and are not exhaustive:

1. Māori participants have their ethnicity recorded (e.g. self-identified).
2. If using metadata, it is used to summarise basic information about MHD (e.g. ethnicity) to make it easier to find, use and reuse for activities such as compliance of HISO.

Discussion

The MHD governance planning and protocol checklist was developed by adapting the Model, and generating questions from The Health Services and Outcomes Kaupapa Inquiry WAI2575, NEAC guideline and the CARE principles (Clark 2019; Hudson et al. 2019; Kukutai et al. 2023a; National Ethics Advisory





[Committee 2019](#)). These four sources and expert advice provided a checklist for the planning and implementation of MHD governance in health settings.

Like Māori models of health, there is synergy between the CONSIDER statement and this MHD governance checklist. The CONSIDER statement focuses on the reporting of Indigenous participation and partnership in research, and this checklist focuses on all aspects of Māori data governance. An example of synergy is *Pou 1*: Data capacities and workforce development in the MHD governance checklist and Prioritisation and relationships in the CONSIDER statement. Both centre Indigenous collaboration and *whānau* Māori-led solutions through different aspects of the research process. These two synergistic approaches help facilitate Indigenous and non-Indigenous researchers and agencies to move closer to health equity for Indigenous peoples as ‘business as usual’.

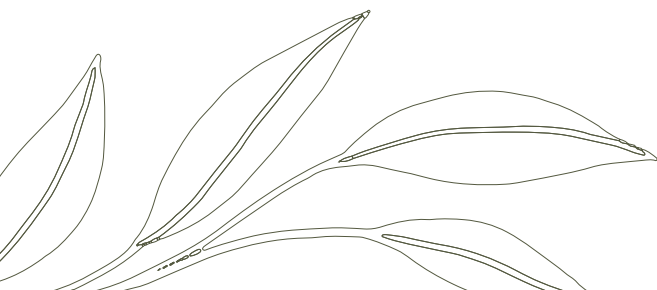
A recent publication highlighted the need for MHD governance support, where the COVID-19 tracer application, a digital contact tracing tool, was assessed against the Model ([Sterling et al. 2024](#)). Results from this analysis indicated that seven of the 24 model criteria were met, and nine were considered to have failed the criteria, and that a tool could be used at the same time as best practice activities, for example the Privacy Impact Assessment used in the Public Sector ([Sterling et al. 2024](#)). Additionally, when agencies are making decisions on national health initiatives, such as the COVID-19 vaccination roll out or using data to inform screening policy (for example the bowel screening ethnic-specific age extension approach), utilising this MHD governance checklist will likely identify proactive opportunities to contribute to achieving health equity, rather than embedding inequity ([Russell et al. 2023](#); [Sterling et al. 2024](#)).

Completing the tool may also help prevent white privilege of resources and access ([Chin et al. 2018](#)).

Intertwined with health equity is anti-racism. Everyday health workforce conversations that uphold social injustices, and include excuses for inaction towards health equity, need to be addressed to change the culture in the health sector ([Came et al. 2025](#)). Enhancing transparency through the use of the MHD governance checklist can enable accountability for researchers and agencies ([Came et al. 2025](#)). It is an expectation that both CONSIDER and MDG checklists are developed together with research proposals and documentation (protocols, ethics approvals) early in the development of project proposals, and the checklist can help early identification of gaps and prompt researchers on specific strategies.

The checklist items from this research were adapted from the eight data *Pou* in *Te Kāhui Raraunga* and form a guide for Māori and non-Māori health researchers and agencies to use to plan for and implement their own MHD governance plan. This addresses a health-specific policy implementation gap identified in the Model report itself. It is likely that as society changes over time, this will have an influence on the prompts within the *Pou*, for example: legal and extra-legal forms of data ownership and rights of *Pou 8*. Therefore, providing an opportunity for future work on what these *Pou* prompts might look like in the years ahead.

Health researchers and agencies may also use this checklist to retrospectively review previous activities to identify areas of success and areas where future improvements could be made. Additionally, health agencies or research groups may use the checklist to make improvements in their capacity, capability, maturity and workforce to achieve the expectations of





MDG in the Model. Planning and implementing MHD governance are important actions that Māori and non-Māori health researchers and agencies can perform to uphold *te Tiriti o Waitangi*. This will facilitate *te Tiriti o Waitangi*-led approaches to MHD governance, facilitate accountability to *iwi*, *hapū* and *whānau* and enable reciprocal relationships.

Conclusion

The MHD governance planning and protocol checklist provides a *te Tiriti o Waitangi* approach for health researchers and agencies that can be implemented alongside current ethical practices, and the checklist is an actionable tool that can be used to contribute to health equity for Māori.

Author contributions

Study concept: S. Crengle. Study design: L. Kremer. Drafting study protocol: L. Kremer, S. Crengle, T. Kukutai. Data collection: L. Kremer. Data analysis: L. Kremer, S. Crengle, T. Kukutai, K. Bartholomew. Reviewing of manuscript for intellectual content: All authors. All authors agreed on the final paper for publication. All authors read and approved the final manuscript.

Declaration of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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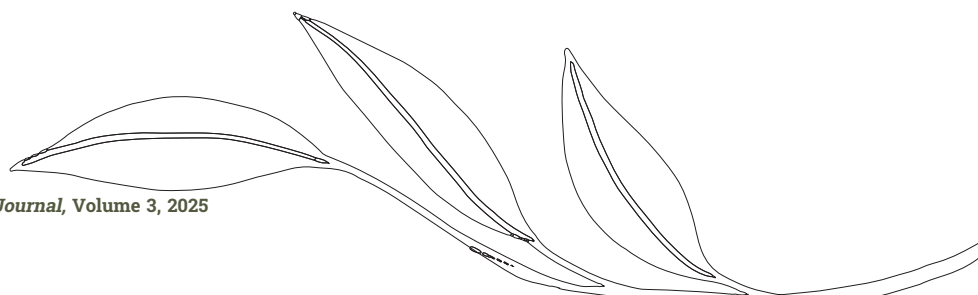
The views expressed in this article are our own and not an official position of any institutions affiliated with the authors.

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Sue Crengle (Kāi Tahu, Kāti Māmoe, Waitaha) is a general practitioner working at Ngāti Porou Oranga, public health medicine specialist, and is a Professor and the Director for the Ngāi Tahu Māori Health Research Unit at Ōtākou Whakaihu Waka (University of Otago). Sue's research primarily focuses on health services research, cardiovascular health, lung cancer screening and implementation science. Sue is making every research activity count towards health equity for Māori.

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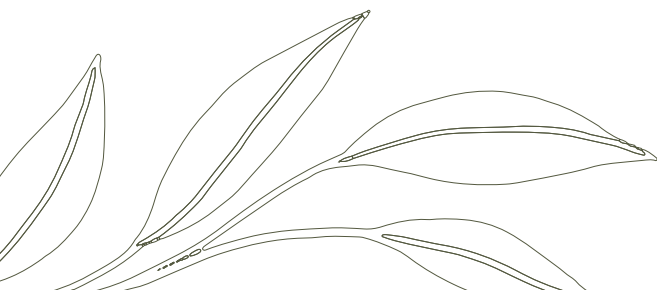
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Supplementary material

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.fnhli.2025.100074>

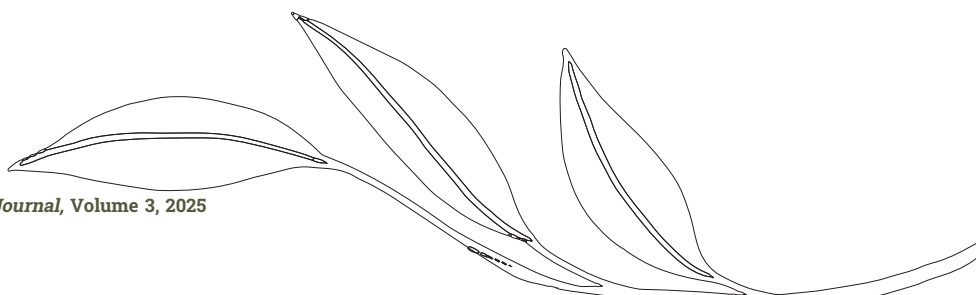
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