

Māori Descent and Iwi Affiliation Data Protocols

HISO 10094:2020

PUBLIC COMMENT OUTCOMES

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1 Purpose

This document summarises the outcomes of public comment on draft standard HISO 10094:2022 *Māori Descent and Iwi Affiliation Data Protocols*.

The protocols define procedures for the standardised collection, recording and output of Māori descent and iwi affiliation data in the Aotearoa New Zealand health and disability system.

The draft was open for public comment on Health Consultation Hub from 27 September to 6 December 2021, advertised through HISO, Stats NZ and Data Iwi Leaders Group channels.

This document summarises the themes, suggestions for improvement and general level of support for the draft standard.

In seeking public comment, HISO noted the following.

- The document is consistent with the **Iwi Statistical Standard and Classification** published by Stats NZ, outlining a set of minimum standards that apply across the health and disability system to all organisations that collect, record and use iwi affiliation data.
- Integration of the protocols into the health and disability system will assist in the ongoing process of improving the quality, accuracy and consistency of iwi affiliation data.
- The protocols are draft and will continue to be developed, based on experience from implementation.

2 Overview of responses

The Ministry of Health, Stats NZ, Data Iwi Leaders Group, Interim Māori Health Authority and Interim Health New Zealand were all represented on the public comment evaluation panel.

HISO is grateful for the interest of the public, and acknowledges the 22 agencies and individuals who responded, providing a total of 176 comments on individual points.

The evaluation panel observed that the new standard had a good overall level of support and there were no comments expressing opposition to the protocols. Many comments offered constructive improvements to the draft, which were incorporated for publication.

Other comments that could not be addressed immediately will be used to inform further development of the protocols.

Questions were raised that are beyond the present scope of the protocols but relate to implementation.

- Who collects the information and what training and resources are provided to help?
- Where will the collected information be held?
- Who (agency/person) will govern the information?
- Who (agency/person) will have access to the information, what type of access and at what level of detail?

2.1 Number of responses

Number of respondents by type

| Respondent type | Total |
|--------------------------------|-----------|
| Government agencies | 3 |
| Private health sector agencies | 6 |
| Māori agencies | 13 |
| Total respondents | 22 |

Number of individual comments by section

| Section | Supported | Opposed | No comment | Other comment |
|--|-----------|----------|------------|---------------|
| General comments | 8 | 0 | 1 | 14 |
| Purpose | 8 | 0 | 4 | 7 |
| Scope | 6 | 0 | 4 | 9 |
| Background | 2 | 0 | 5 | 15 |
| Collecting Māori descent and iwi affiliation data | 4 | 0 | 1 | 34 |
| Classifying, coding and recording Māori descent and iwi affiliation data | 7 | 0 | 4 | 15 |
| Output of Māori descent and iwi affiliation data | 3 | 0 | 4 | 8 |
| Adoption and implementation | 2 | 0 | 2 | 9 |
| Totals | 40 | 0 | 25 | 111 |

2.2 General comments received

General comments received covered the following points.

- Rules need to be established over the information captured, covering:
 - who has access (person, agency), and the type of access (view, edit, and for what use)
 - right to share data – with whom and for what purpose, including a right to forbid or deny access or the sharing of information at an individual level
 - equity and equality factors.
- Collectors and storing agencies will need training in both technical and cultural factors.
- It will be important to maintain engagement with the Māori leadership groups who have been involved.
- The ongoing implementation of the protocols needs a formal and ongoing review commitment.

Rules over the information capture will be informed by other, more broadly focused work on information governance for inclusion in the next edition of the protocols.

The need for the right tools and training for people to collect information is acknowledged as implementations get underway.

Continued engagement with the Data Iwi Leaders Group, Māori data specialists and Māori leadership groups will be critical.

The protocols will be reviewed within the first year of publication.

3 Summary of comments by section

3.1 Comments on the purpose of the protocols

The stated purpose of the protocols is to document a consistent and reliable approach to the collection of Māori descent and iwi affiliation information, in a way that is accessible, connected and relevant to Māori, addresses findings of the **Waitangi Tribunal in Hauora: Report on Stage One of the Health Service and Outcome Kaupapa Inquiry** (Wai 2575), supports delivery of **Whakamaua: Māori Health Action Plan 2020–25** (*Whakamaua*), and follows recommendations of the **Health and Disability System Review** in terms of improving equity of health outcomes for Māori.

The key comments received made the following suggestions.

- Establish a 'use principle' covering both access to and availability of information captured.
- Capture disability information as an aid to meeting the **NZ Disability Strategy 2016-2026** (specifically **Whāia Te Ao Mārama 2018-2022 | Māori Disability Plan**).
- Capture hapū, whānau and marae affiliations as an aid to meeting *Whakamaua's* goals.

Other more broadly focused work is underway that will define rules governing access to personal information collected. A 'use principle' is worthwhile consideration for future development of the protocols.

The request for protocols to collect disability information is noted, although out of scope for this standard.

The protocols in their present form are focused on iwi affiliation and do not extend to hapū.

3.2 Comments on the scope of the protocols

The scope of the protocols is to outline the minimum standards that apply across the health and disability system to collecting, recording and using iwi affiliation data. The draft protocols do not, and were not intended to, speak to the ownership or storage of iwi affiliation data.

While the draft protocols do comment on the output of the information, this is by way of direct reference to the Tino Rangatiratanga and Active Protection principles of Te Tiriti.

The key comments received covered the following points.

- Respondents need an ability to control who can and cannot access their data. This also should address the issue of sovereignty generally.
- The protocols need a better definition of where the information is to be held and what it is to be used for.
- The scope should be revised and consideration given to including a wider range of participants, for example, disability planners, hapū, whānau, whakapapa and marae services.

These matters of scope are useful input to further development of the protocols. Other work is underway that will help to answer the point on information governance.

3.3 Comments on the background to the protocols

This section provides background to the protocols and the purposes for collecting iwi affiliation data. It references the Ministry of Health's **Te Tiriti o Waitangi Framework**, provides the definitions of Māori descent and iwi affiliation as contained in the **Iwi Statistical Standard and Classification**, and provides guidance on achieving data quality.

The key comments received covered the following points.

- There needs to be consistent formats of information (equivalent to the census) to enable health outcome analysis.
- Access to the data is an essential fundamental.
- Move the section on Te Tiriti to the Purpose section.
- Include proper cultural advisor representation as part of system operation.
- There should be more focus on outcomes.

This section of the protocols was updated as a result.

3.4 Comments on the protocols for collecting Māori descent and iwi affiliation data

This section details the proposed processes for collecting Māori descent and iwi affiliation data from a person's perspective. It notes that data collectors in the health and disability sector can often be administrators, clerks and health professionals. Respondents giving Māori descent and iwi affiliation information tend to be patients, consumers and clients, as well as members of the health workforce when filling in human resources forms.

The key comments received covered the following points.

- Ensure the system is insensitive to macrons and clarify 'as you type' comments.
- Review the text related to assisted responses and trusted delegates (explain who this includes).
- Record hapū and ensure whakapapa mana is protected. Include Cook Islanders.
- Stats NZ information – change wording in relation to 'set by', review iwi that Stats NZ does not recognise, state which surveys are identified, add copy of census form.
- Ensure collectors are appropriately trained – covering cultural awareness and competence, including Te Reo literacy.
- Consider a broader approach to collections and documentation forms, such as accessibility, variations to format, telephone and that verbal is 'not recommended'.
- Rephrase and clarify descent questions (suggested text provided).
- Ensure independence from the Crown is maintained and consider if other agencies should be collecting this data – particularly separate from the electoral roll system.
- Include reference to Health Information Privacy Code.

A number of these constructive suggestions were used to improve the text.

3.5 Comments on the protocols for classifying, coding and recording Māori descent and iwi affiliation data

This section details how Māori descent and iwi affiliation data provided by a respondent is classified, coded and recorded. The recording process uses the standard classification to identify the appropriate codes and then stores the identified codes.

The key comments received covered the following points.

- Include capture of iwi and hapū.
- Include capture of Pasifika information.
- Capture and retain all original responses.
- Allow for the capture of rohe, grouping, geographic and social factor information.
- Consider the use of an existing national database as the collection point.

These were constructive comments, although recording hapū is not currently within the scope of the protocols, nor is Pasifika information.

The protocols are intended to capture coded information whenever possible but allow for the original text to be recorded for any response that cannot be accurately coded.

Rohe is used to distinguish iwi with the same names so that the correctly coded iwi can be recorded.

3.6 Comments on the output of Māori descent and iwi affiliation data

This section sets out that output using Māori descent and iwi affiliation data is for the purposes specified under the Tino Rangatiratanga and Active Protection principles of Te Tiriti, specifically:

- ‘Māori self-determination and mana motuhake in the design, delivery, and monitoring of health and disability services’
- ‘ensuring that it [the Crown], its agents and its Treaty partner are well informed on the extent and nature of both Māori health outcomes and efforts to achieve Māori health equity’.

The key comments received covered the following points.

- Allow for the capture and recording of collective information, including hapū.
- Establish formal co-governance procedures, clearly setting out use and access rules.
- Provide a range of accessible formats for data collection and ensure that descent and affiliation data is correctly segregated.
- Ensure there is an ability to allow for people who are living out of their iwi/rohe area.
- Consider updating the information every five years.

Co-governance arrangements are being worked out around the Tātai iwi affiliation data collection, which is the first implementation.

Common forms and materials for collecting iwi affiliation data will be developed.

3.7 Comments on adoption and implementation

The key comments received covered the following points.

- The implementation timeframe is needed to allow the development of local systems.
- Include information that covers population groups and disability information.
- Ensure there is an appropriate update process for information.
- Ensure the ongoing governance function includes representation from the Data Iwi Leaders Group and other Māori data specialists.

This section of the protocols was updated to say more about the Tātai online iwi affiliation collection tool and its operation and governance, which will transition from the Ministry of Health to Māori.