

**Te Aka Whai Ora**  
Māori Health Authority

# Action plan for achieving high quality ethnicity data in the health and disability sector

A report for Te Aka Whai Ora:  
Māori Health Authority

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*Kia mau koe ki te aka matua, kei mau  
koe ki te aka tāepa.*

*Hold fast to the parent vine, take not hold  
of the loose vine.*

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Part 1:

# ➤ Background

*“Māori have the right to be counted.  
Being counted is an acknowledgement  
of being valued”*

*(Paine et al. 2020)*

## State of the issue

High quality ethnicity data are critical for Māori health improvement, and it is the responsibility of the entire health system to collect, record and report ethnicity data in the ways set out in the HISO 10001:2017 Ethnicity Data Protocols (the protocols). Despite the protocols being in existence for nearly 20 years, there is evidence that they are not being adhered to and Māori have continued to be systematically undercounted over this time period (Harris et al. 2022, Cleary 2021, Reid et al. 2016, Cormack and McLeod 2010). Recent audits of ethnicity data quality show that one in five Māori (21%) were not identified as Māori on the National Health Index (NHI) when compared to self-identified ethnicity recorded on the Census (Harris et al. 2022, Cleary 2021). The quality of ethnicity data is consistently worse for Māori males than Māori females, and is particularly poor for those ages 20–24 years, where the NHI misses 30%, or almost one in three Māori (Harris et al. 2022).

There is an urgent need for leadership and a coordinated and ongoing response across the health sector to achieve high quality ethnicity data. The recent health system reforms and establishment of Te Aka Whai Ora and Te Whatu Ora offer an important opportunity to enable national consistency in ethnicity data protocol compliance and accountability, and to provide leadership for the whole health sector.

## Why are high quality ethnicity data important?

Māori have the right to be counted. Being counted is an acknowledgement of being valued (Paine et al. 2020).

High quality ethnicity data are fundamental to a health system that aims to improve Māori health and eliminate ethnic health inequities. High quality ethnicity data need to be timely, valid, reliable, and useable (Cormack and McLeod 2010). Māori have the right to be counted and to identify their own ethnicity (Harris et al. 2022).

Ethnicity data are used in many ways across the health system. For example, accurate ethnicity data are required to make sure that enough **funding** is allocated to address Māori health needs, and that we can identify Māori individuals for the delivery of **targeted health services** such as cardiovascular risk assessments and bowel screening at an (appropriately) earlier age. If NHI ethnicity is used for funding and targeting of health services, the systematic undercounting will lead to continued underfunding and underservicing of Māori health needs, with Māori missing out on care. Furthermore, when ethnicity data are used in research/analysis or as training data for algorithms, the systematic poor quality for Māori will be built into those systems with impacts on recommendations for treatment, and access to care for Māori. Ethnicity data are also fundamental to measure Māori health needs and to **monitor the health system's performance** in providing high quality and accessible care for Māori, as well as increased **Māori workforce** representation. Providing ethnicity data to Māori is also important in planning for Māori led health needs analyses and monitoring the Crown's responsiveness to Māori health equity.

## How is ethnicity defined in the health and disability sector?

Stats NZ is responsible for the official standard for ethnicity. This applies to all of Government including the Health and Disability sector. The current official definition of ethnicity in the protocols comes from the Statistical Standard for Ethnicity V1.0.0 (Stats NZ n.d.). This Statistical standard for ethnicity is currently under review.

## Why do we use ethnicity in health?

Historic and political contexts, including racism and colonialism, shape the ways in which ethnic groups, including Māori are conceptualised, defined and measured in Aotearoa New Zealand (NZ) (Cormack and Kukutai 2016). Race and ethnicity are social constructs that reflect the processes that drive differences in social outcomes (Williams and Mohammed 2013). They are not measures of biological (e.g. genetic) differences (Cormack 2010). Ethnicity as a social category influences peoples experiences and outcomes. Therefore, ethnicity is particularly relevant to the understanding and measurement of health and health equity, given that the biggest influences on health and health inequities are the social determinants of health (e.g. racism, socioeconomic status, access to and quality of healthcare) (Marmot et al. 2008, Robson and Harris 2007).

*“Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self-perceived, and people can belong to more than one ethnic group.”*

An ethnic group is made up of people who have some or all the following characteristics:

- > a common proper name
- > one or more elements of common culture which need not be specified, but may include religion, customs, or language
- > unique community of interests, feelings and actions
- > a shared sense of common origins or ancestry, and a common geographic origin.

Source: Ministry of Health. HISO 10001:2017 Ethnicity Data Protocols

Self-identification as a key component of ethnicity, aligns with principles of self-determination and the right for Māori to name ourselves as Māori (Robson and Reid 2011, Te Rōpū Rangahau Hauora a Eru Pōmare 2000).

Ethnicity and descent are different but related measures of Māori identity, with a lot of overlap in the individuals included in each population. ‘Descent’ refers to biological ancestry and ‘ethnicity’ to cultural affiliation. Census data show that almost all people (99%) who identify their ethnicity as Māori also report having Māori descent (Kukutai 2004), and 84% of people with Māori descent also report being of Māori ethnicity (Sporle et al. 2019).

Although there are issues with the quality of ethnicity in health datasets, it is the measure of Māori identify that is routinely collected and used in health monitoring and planning; descent is not. Māori descent and ethnicity are both collected in the NZ Census and birth/death registration. However, descent is not collected for everyone (other than Māori descent) and therefore limits our ability to examine equity for other ethnic groups (e.g. Pacific) and also for Māori where we may want to make comparisons to European (as the most privileged group).

There may be times when descent is a more appropriate measure of Māori identify. For example, descent may be used in genetic research. Descent is also used in eligibility for entry to Māori tertiary education programmes (Curtis and Reid 2013). This is based

upon an understanding that colonial assimilation policies have excluded many Māori with whakapapa from accessing and identifying with Māori culture, and therefore Māori ethnicity. Using ethnicity in this context, would deny some individuals with Māori whakapapa to access interventions and entry to programmes to which they are eligible. Upholding the Indigenous rights of Māori in this situation requires the use of descent over ethnicity.

## Why do we need to ask for ethnicity in such a standardised way?

There have been changes to the Census ethnicity question over time, that are reported in detail elsewhere (Cormack and McLeod 2010). The way we collect ethnicity data including any changes to the question used, can have important impacts on the number of individuals recorded as Māori and the number of individuals with multiple ethnicities. This has implications for monitoring ethnic-specific trends and health inequities over time (Te Rōpū Rangahau Hauora a Eru Pōmare 2000).

One example was the change in wording of the 1996 Census question, and the inclusion of extra response options for “other European”. Compared to previous Censuses, these changes encouraged more individuals to identify with multiple ethnic groups. Further, these responses were more likely to be based on ancestry than were responses to the 1991 Census ethnicity question (ACNeilsen 1999).

The protocols require collection, recording and reporting ethnicity data in ways that reflect that ethnicity is self-identified (unless the respondent is unable), that people may identify with more than one ethnic group (multiple ethnicities) and that ethnicity may change over time and so must be recollected

at least every three years (ethnic mobility). The standard ethnicity question for the health and disability sector is currently the Stats NZ 2018 Census ethnicity question (Figure 1), with guidance provided in the protocols for asking this in different formats e.g. on paper, verbally, online, and by proxy as required.

Figure 1: Standard ethnicity question

Which ethnic group do you belong to?  
Mark the space or spaces which apply to you.

- New Zealand European
- Māori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian
- other such as *DUTCH, JAPANESE, TOKELAUAN*. Please state:

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Source: Statistics New Zealand, 2018 Census

Where the actual graphic is not used, the minimum requirements are:

- a. The opening words of the question must be the same. "Which ethnic group do you belong to? Mark the space or spaces that apply to you."
- b. The listed ethnicities must all be present and in the order shown in Figure 1. No additional categories may be added. It is preferable that the categories are listed vertically.
- c. Any collection mechanism must allow multiple ethnic groups to be selected and must allow multiple ethnic groups to be entered in the 'other' section.

Source: Ministry of Health 2017



Part 2:

## > Action plan

*A critical element of improving ethnicity data quality is leadership and the elevation of ethnicity as a priority action for the health sector in efforts to attain equity.*

### What should be done/ next steps

Ethnicity data quality for Māori is problematic and requires urgent attention. A number of tools to achieve high quality ethnicity data already exist in the protocols and Ethnicity Data Audit Toolkits (EDAT). Responsibility for high quality ethnicity data sits with the entire health sector and requires adherence to the protocols. The HISO 10001:2017 Ethnicity Data Protocols set clear standards, including the need for ethnicity data to be collected on an ongoing basis (not as a one-off activity). There is evidence that the protocols have not been adequately implemented and are not being adhered to, both because of a lack of health sector knowledge of the importance of ethnicity data and the contents of the protocols, but also in some cases because systems (including IT systems) do not allow adherence with the protocols (Cormack and McLeod 2010, Neuwalt et al. 2014) (Appendix 1). There are already indicators for ethnicity data quality in the 2021/22 DHB non-financial monitoring framework and performance measures report (Ministry of Health 2021a), Ngā Paerewa Health and Disability Services Standard NZS 8134:2021 (Standards NZ, 2021) and the Foundation Standards for primary care (RNZCGP n.d.), the latter of which are attached to government funding. However, these indicators require strengthening and expansion to include a wider range of settings (e.g. outside of primary care). It is unclear how well these indicators are monitored and compliance enforced.

It appears that compliance with the protocols to date has relied upon trust in providers with some auditing of the quality of ethnicity data held in databases by providers and researchers (Harris et al. 2022, Cleary 2021). To date, education and auditing have largely focused at the level of local and regional health providers (e.g. primary care practices and hospitals), with gaps at the central health agency level such as Manatū Hauora, Te Whatu Ora and Te Aka Whai Ora who are key users and, at times, primary data collectors e.g. workforce surveys, New Zealand Health Survey. There appears to be no identifiable person or group with overall responsibility for ethnicity data quality and no co-ordinated system in place to ensure accountability for compliance with the protocol processes and high quality ethnicity data at all levels.

### Scope of this action plan

The following action plan is focused on the collection and recording of high quality ethnicity data in line with the processes outlined in the ethnicity data protocols. The reporting of ethnicity data in health statistics and monitoring, including categories, comparators and denominators is also important but is outside of the scope of this report.

High quality ethnicity data are the responsibility of the entire health sector. This report was commissioned by Te Aka Whai Ora and focusses on actions for Te Aka Whai Ora, along with other central health agencies including Te Whatu Ora and Manatū

Hauora, and for local and regional providers (including Te Whatu Ora). The protocols also cover health workforce ethnicity data. The protocols apply to many agencies, organisations and health providers. While all organisations may not be mentioned in this report, the general issues and approaches to addressing ethnicity data quality are likely to be similar.

There are a number of existing tools to achieve and monitor ethnicity data quality, including:

- > HISO 10001:2017 Ethnicity Data Protocols. (Ministry of Health 2017)
- > 2021/22 DHB non-financial monitoring framework and performance measures (Ministry of Health 2021a)
- > The Foundation Standard (RNZCGP n.d.)
- > Ngā Paerewa Health and Disability Services Standard NZS 8134:2021 (Standards NZ 2021)
- > Primary Care Ethnicity Data Audit Toolkit (Ministry of Health 2021b)
- > Hospital Ethnicity Data Audit Toolkit (Ministry of Health 2021c)

In addition, other resources and workplans exist and are at various stages of development (Appendix 2). There may be other resources not identified here.

This report presents our initial thinking on key priority areas to improve ethnicity data quality. Ongoing effort will be required in order to achieve and maintain data quality in ways that reflect both changes over time to the health system, as well as any

reviews of ethnicity data standards. The following sections of this report outline potential roles and actions for Te Aka Whai Ora, followed by actions for the wider health sector under the key areas of: leadership, knowledge, compliance, and accountability/monitoring. While we have divided actions into these headings, all of the proposed actions are important and may need to occur in parallel.

The scope of the report is limited to ethnicity data quality, but there are other sources of demographic data that are of importance to Māori and should use standardised processes such as gender identity and disability. Establishing good practices with respect to ethnicity data could have positive flow on effects for the quality of other demographic data. While not covered in detail in this report, Māori Data Sovereignty is important to consider for all Māori data. Improved ethnicity data quality will apply to all New Zealanders with important implications for monitoring health and health equity for other ethnic groups.

### The role of Te Aka Whai Ora in ethnicity data quality improvement

Key actions for Te Aka Whai Ora:

- > Make ethnicity data quality a high priority with oversight by ELT and the Board
- > Identify a lead agency responsible for achieving high quality ethnicity data and work alongside this agency to contribute Māori health and equity expertise

- > Ensure all Te Aka Whai Ora staff receive training on the Ethnicity Data Protocols and the implications of poor ethnicity data quality on Māori health and equity
- > Ensure Te Aka Whai Ora and its commissioned agents are compliant with Ethnicity Data Protocols
- > Assist in the development of any indicators for ethnicity data quality
- > Monitor sector accountability (including that of the lead agency) for high quality ethnicity data
- > Monitor the quality of ethnicity data in relation to Māori health and health equity

The current quality of ethnicity data and the undercounting of Māori in health data should be of major concern to Te Aka Whai Ora given the broad ranging implications for Māori health and equity. As noted, high quality ethnicity data are the responsibility of the entire health sector as a variable for all New Zealanders with ethnic health inequities experienced by groups other than Māori. The responsibility to ensure high quality ethnicity data does not sit solely with Te Aka Whai Ora, although it has an important role to play especially given the implications for Māori health equity and Māori data sovereignty. Te Aka Whai Ora is well positioned to take a leadership role in urgently advancing improvements in ethnicity data quality across the sector by promoting ethnicity data quality as a priority and holding the health system accountable for adherence to

protocols and achieving high quality ethnicity data on an ongoing basis.

Te Aka Whai Ora should work with Te Whatu Ora and Manatū Hauora to identify a **lead agency** responsible for achieving high quality ethnicity data. Roles and responsibilities, as well as ongoing processes for engagement and accountability should be developed between the lead agency and Te Aka Whai Ora.

Te Aka Whai Ora should lead by example, ensuring all staff receive training and have a good understanding of what ethnicity is, how it is used, its current limitations, and knowledge of the ethnicity data protocols. Te Aka Whai Ora staff should also understand the implications of ethnicity data quality for their own work as well as more broadly across the sector.

Te Aka Whai Ora has a monitoring function which in the context of ethnicity data quality should include monitoring sector accountability (including that of the lead agency) for high quality ethnicity data, ensuring compliance with the protocols and standards by directly commissioned providers, and monitoring the quality of ethnicity data in relation to Māori health and health equity (possibly analysed and provided by the lead agency). Te Aka Whai Ora who should also be involved in the development of any indicators for ethnicity data quality. These may include indicators and health sector standards to assess adherence to the protocols and the quality of ethnicity in health data collections.

As commissioning agents, Te Aka Whai Ora have responsibility to ensure their contracted providers are aware of ethnicity data requirements and are compliant with ethnicity data protocols. Potential levers to strengthen compliance should be considered e.g. contract requirements, monitoring and performance attached to funding. Ongoing data quality processes outlined for the health sector in the sections below will also apply to Te Aka Whai Ora and its commissioned service providers.

## Leadership

Key action for Te Aka Whai Ora, Te Whatu Ora and Manatū Hauora:

- › Identify a lead agency for the achievement of high quality ethnicity data in NZ

Key action for the lead agency:

- › Gain and maintain oversight of ethnicity data quality and develop and deliver a co-ordinated ethnicity data quality improvement program.

A critical element of improving ethnicity data quality is leadership and the elevation of ethnicity as a priority action for the health sector in efforts to attain equity. An initial step in achieving this is identifying a lead agency with oversight of a quality improvement program for ethnicity data to ensure a coordinated approach across the health sector (i.e. a cross sector agency workplan). This will include education, implementation of Ethnicity Data Protocols, monitoring compliance with the protocols and

HISO Standards, and monitoring ethnicity data quality. As noted previously, ethnicity data quality is the responsibility of the whole sector with implications for ethnic groups in addition to Māori e.g. Pacific health and inequities. A priority action in achieving high quality data is the implementation of the ethnicity data protocols across the sector. For this reason, Te Whatu Ora may be the most appropriate lead agency at this time.

While the lead agency will have overall ownership and leadership of ethnicity data, they will work with various directorates, agencies and providers in the development and implementation of a quality improvement program for high quality ethnicity data. This includes agencies such as Statistics New Zealand e.g. for ongoing review of protocols and supporting tools such as Ethnicity Data Audit Toolkits (EDATs) following any changes in the ethnicity standard; Manatū Hauora e.g. for central data quality monitoring. The lead agency should also work closely with Te Aka Whai Ora as described above, and Pacific health groups. An important first step for the lead agency will be an environmental scan to identify existing plans, resources, and activities on ethnicity data quality and how these may need to be reviewed and/or strengthened. For example, we are aware that there is an Ethnicity Data Protocols Adoption Roadmap that sits with Data and Digital in Te Whatu Ora (previously Manatū Hauora) (Appendix 2) and an e-Learning tool that has been developed for data collectors and recorders (<https://learnonline.health.nz/login/index.php>).

## Knowledge

Key actions for the health sector:

- › Improve understandings of what ethnicity is, and why it is important for Māori health and ethnic health inequities
- › Improve knowledge of the Ethnicity Data Protocols

Central health agencies such as Te Whatu Ora, Manatū Hauora and Te Aka Whai Ora have important roles as collectors of ethnicity data (including through health workforce surveys) and as users of ethnicity data. All staff within these central agencies should lead by example by understanding what ethnicity is, why it is collected, and by applying the protocols for the collection, recording and reporting of ethnicity data across all their work.

The protocols have a broad range of users, including people working within the health system or interacting with it. All identified 'users' of the ethnicity data protocols should be aware of the protocols and have a good understanding of the particular areas that apply to their work. Identified protocol users include: collectors and processors of ethnicity data; users of ethnicity data including those involved in: research, service planning (including workforce) or quality control, monitoring performance and targeting resources, development of funding formula; and, health information software developers (Ministry of Health 2017).

The ethnicity data protocols themselves are currently the best resource for understanding the requirements of ethnicity data

collecting, recording and reporting. There is also the potential for the development of other educational tools to both improve understanding of ethnicity data in general as well as the protocols more specifically. Currently there is an e-learning ethnicity module available through Manatū Hauora and Te Whatu Ora, however, there are a number of errors/problems with this that would need addressing before promoting this more broadly. In addition, data users should understand the current ethnicity data quality issues in health data e.g. undercounting of Māori and the implications for data use, including access to care for individuals.

## Compliance

Key actions for the health sector:

- › Ensure collection and recording of ethnicity data are compliant with Ethnicity Data Protocols
- › Ensure IT systems are compliant with the Ethnicity Data Protocols

In addition to ensuring their own knowledge of and compliance with the protocols, central health agencies such as Te Whatu Ora, Manatū Hauora and Te Aka Whai Ora as commissioning agents hold a responsibility to ensure that the wider health system is also educated and compliant with the ethnicity data protocols. Levers to strengthen compliance should be considered. For example, contracting requirements to demonstrate compliance with the protocols, plans to address non-compliance and performance attached to funding. As noted, the



protocols themselves are a great first resource to educate staff, with other tools in development. Compliance checklists and audit tools already exist for health care providers such as primary care and hospitals (Ministry of Health 2021b,c). However, there are gaps for central and regional health organisations and agencies that collect data and/or use ethnicity data, including workforce data.

IT systems are commonly discussed as a key barrier to achieving high quality ethnicity data collections (Cormack and McLeod 2010). Part of the challenge is that despite being a relatively small country, we have a wide range of IT systems in use by the NZ health sector coming from a range of different providers. Information systems should meet minimum standards outlined in the protocol. However, there is variable compliance with the protocol requirements, including the ability for IT systems to capture up to six ethnicities per individual. Many of these systems are connected, and so even where data are collected and recorded in line with protocol requirement in one setting, quality may be lost if the data are transferred to other systems that are not protocol compliant.

The recent health system reforms create an important opportunity to achieve national consistency in ethnicity data protocol compliance. An important role for Te Whatu Ora will be rationalising the number of IT systems in use and ensuring that new and existing systems are compliant with statistical standards, including those for ethnicity data collection, but also for other demographic data such as gender.

IT systems however, should not only be viewed as potential barriers to high quality ethnicity data collection, but also as key enablers. This may include the development of systems (e.g. through Manage My Health or check-in kiosks) that allow patients to view and update their own ethnicity data, timestamped ethnicity data to show the 'freshness' of data, system flags to prompt the required 3-yearly collection of ethnicity data from individuals or to identify those with not stated and missing ethnicity data, and automation of systems to reduce the manual steps of checking ethnicity codes and the prioritisation to three codes while systems are adjusted to accept the required six. In addition, there may be potential to develop interactive digital versions of elements of the ethnicity data audit toolkits.

### Accountability/Monitoring

Key actions:

- > Monitor compliance with Ethnicity Data Protocols with associated accountability mechanisms
- > Monitor ethnicity data quality at national, regional and local levels

The monitoring roles of Te Whatu Ora, Manatū Hauora and Te Aka Whai Ora should include indicators of **protocol complaint processes** as well as the regular measurement of the **quality of data** recorded within national health datasets (Table 1). At a minimum, process compliance should require reporting on the completion of EDAT systems compliance checklists by all providers (as well as by central health agencies

themselves with adapted tools), an indication of the levels of compliance and, where required, an action plan developed for rapidly achieving compliance. In addition, contracts should allow for random checks of systems' compliance and attached financial incentives or penalties for non-compliance.

In addition, health workforce ethnicity data collection needs to comply with the protocols. This includes workforce surveys by central health agencies and registration data collected by responsible authorities for regulated workforces under the Health Practitioners Competence Assurance Act 2003. There is currently a gap in the assessment of ethnicity data quality in health workforce collections.





**Table 1 Draft indicators of Ethnicity Data Protocol compliance and ethnicity data quality**

Aim	Examples of potential indicators
Demonstrated knowledge of the Ethnicity Data Protocols	% of staff (central health agency staff and other healthcare providers) that have undertaken training and have completed and passed an assessment of protocol contents (e.g. e-learning module or a quiz)
Demonstrated compliance with the Ethnicity Data Protocols	<p>Completion of systems compliance checklists, and development of quality improvement plans where necessary. Checklists currently exist for primary care and hospitals, but could be adapted for additional users or roles e.g. central health agencies, planning and funding, policy, commissioning, quality assurance, workforce development and research functions.</p> <p>Proportion of ethnicity data records that have been updated within the last three years. This action may require some systems changes to record (date stamp and recording if answers unchanged).</p>
Improved data quality	<p>National linkage (reported at national, regional and local levels) of <u>self-identified</u> (not enumerated) census ethnicity data (as the reference standard) to NHI (or other health datasets). Indicators of quality will include:</p> <ul style="list-style-type: none"> <li>&gt; the degree to which health data matches (full match, partial match or total mismatch) that recorded within the Census self-identified subset,</li> <li>&gt; measurement of undercount of Māori (and Pacific) and whether there is differential misclassification (i.e. a larger level of misclassification in some ethnic groups than others)</li> <li>&gt; comparison of the proportion of each ethnic group on the Estimated Resident Population, Census, and Health datasets,</li> <li>&gt; the proportion of multiple ethnicities, and</li> <li>&gt; the proportions of not stated, refused to answer, and missing</li> </ul> <p>Self-audits by providers and central health agencies using EDAT tools (including tools specifically developed for workforce data quality)</p>

The protocols require a fresh collection of ethnicity data at least every three years. An indicator of the timing of collection could measure the proportion of ethnicity data that has been collected within the past three years. This indicator requires further investigation into the inclusion and accessibility of timestamping and recording source (e.g. primary care, hospital) fields within ethnicity data collections.

Regular monitoring of ethnicity data quality for users of health services could occur centrally, through linkage to self-identified Census ethnicity data (as the reference standard). Indicators of quality will include the degree to which health data matches that recorded within the Census self-identified subset and differential mismatch, comparison of the proportion of each ethnic group on the Estimated Resident Population, Census and Health datasets, the proportion of multiple ethnicities, and the proportion of not stated and refused to answer codes. All of the above indicators can be presented nationally, but also by region and potentially by providers to identify areas/providers that need further education and assistance with their protocol compliance. Random compliance audits could be requested where ethnicity data quality is poor.

Assessing ethnicity data quality for local providers using the Primary Care and Hospital Ethnicity Data Audit Toolkits (Ministry of Health 2021b, Ministry of Health 2021c) should

be a lower priority than ensuring compliance with the protocols given that there is already good evidence that there is an issue with ethnicity data quality and inconsistent compliance with the protocols. It is also possible that the quality of ethnicity data for local and regional providers could be assessed more efficiently by central health agencies through data linkage. However, it is important to consider the implications of Māori data sovereignty in the processes of data linkage, for example consent and limiting linkage to that required to answer predetermined questions.

There are already standards and performance measures for health service providers to collect high quality ethnicity data. There are Tier 2 indicators for ethnicity data quality outlined in the 2021/22 DHB non-financial monitoring framework and performance measures report: **PH02: Improving the quality of ethnicity data collection in PHO and NHI registers** (Ministry of Health 2021a). These state that, "DHBs are required to provide six-monthly updates identifying:

- > the percentage of PHOs that have undertaken an audit using EDAT in the past three years
- > PHOs' most recent Stage 3 EDAT performance (i.e. level of match in ethnicity data)
- > the percentage of PHOs that have reported improvement in quality of ethnicity data collection".

Positioning ethnicity data quality as a Tier 2 indicator suggests that quality is less important than use, given that many Tier 1 indicators are monitored by ethnicity. Elevating ethnicity data quality indicators to Tier 1 should be considered. The above ethnicity data quality indicators focus on PHOs, and, although referring to NHI data quality as important, will only impact this via PHOs. For example, they do not include hospitals, primary care providers or central health agencies that all have an important role in improving ethnicity data quality. In addition, the indicators are: poorly defined (and need to be reviewed, and expanded to capture the responsibilities of all of the health sector); the PHO audit toolkit is not publicly available and therefore it is not possible to know what is meant by the indicators (e.g. “stage 3 EDAT performance and improvement in quality of ethnicity data collection”); and, the reporting on these performance measures is not available online (despite the document indicating this). This limited approach to monitoring is inadequate to address the ethnicity data issues we currently have (Harris et al. 2022).

In 2022, an updated version of Ngā Paerewa Health and Disability Services Standard NZS 8134:2021 came into effect with application to providers of fertility services, primary birthing centres, hospices, overnight hospital inpatient services (public and private), age-related residential care, residential addiction, mental health, and disability services. (Standards New Zealand, 2021) As part of the certification process, providers must be audited against the standards by

a designated auditing agency. Two standards directly refer to ethnicity:

- > 2.4.6: Information held about health care and support workers shall be accurate, relevant, secure, and confidential. **Ethnicity** data shall be collected, recorded, and used in accordance with Health Information Standards Organisation (HISO) requirements
- > 2.5 Te Tiriti: Service providers collect, store and use quality **ethnicity** data in order to achieve Māori Health equity.

The Sector guidance for Ngā Paerewa includes suggestions to review data quality regularly, use the EDATs, collect workforce ethnicity data where it is missing and collect, record and use ethnicity data in accordance with HISO 10001 2017: Ethnicity Data Protocols. (Ministry of Health 2021d).

Another performance requirement identified was the RNZCGPs Foundation Standard (RNZCGP n.d.), which is a three yearly requirement for primary care practices to receive Government funding. These state that primary care practices need to align with the current ethnicity data protocols. However, the only aspect that is assessed is the ethnicity question included on the practice enrolment form, with many publicly available current examples of non-compliance (Appendix 1). There may need to be additional training of the assessors and broadening of the assessment of compliance with the protocols in addition to checking the ethnicity question.

## Conclusion

High quality ethnicity data are critical for Māori health improvement and equity. It is the responsibility of the entire health system to comply with ethnicity data protocols. There is an urgent need for leadership and a coordinated and ongoing response across the health sector, with strengthened accountability and monitoring mechanisms, to achieve high quality ethnicity data.



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## Appendices

### Appendix 1: Examples of current, publicly available, non-compliant ethnicity questions in the health sector

Example 1: Primary care enrolment form 2022

Ethnicity/Nationality:

Example 2: Primary care enrolment form 2022

**Ethnicity\*:**

**WHICH ETHNIC GROUP DO YOU BELONG TO? (YOU MAY SELECT UP TO THREE ETHNICITIES):**

NZ European/Pakeha <sup>11</sup>	<input type="checkbox"/>	Cook Island Maori <sup>32</sup>	<input type="checkbox"/>	Chinese <sup>42</sup>	<input type="checkbox"/>
Maori (please state iwi) <sup>21</sup>	<input type="checkbox"/>	Tongan <sup>33</sup>	<input type="checkbox"/>	Indian <sup>43</sup>	<input type="checkbox"/>
Samoan <sup>31</sup>	<input type="checkbox"/>	Niuean <sup>34</sup>	<input type="checkbox"/>	Other Ethnicity (Please state) <sup>61</sup>	<input type="checkbox"/>

Example 3: Primary care enrolment form 2022

Which ethnic group do you belong to?	
Mark the space or spaces which apply to you *	
Māori, Your Iwi:	
Fijian	
Tongan	
Samoan	
Indian	
Niuean	
Chinese	
Middle Eastern	
Cook Islands Maori	
New Zealand European	
Other such as DUTCH, JAPANESE, TOKELAUAN. Please state:	

Example 4: Online booking form 2022

**Ethnicity**

NZ European

Māori

Pacific Peoples

Asian

Middle Eastern / Latin American / African

Other ethnicity

Example 5: Online enrolment form 2022

Child's ethnicity 1 \*

- Select -

Child's ethnicity 2

- None -

Child's ethnicity 3

- None -

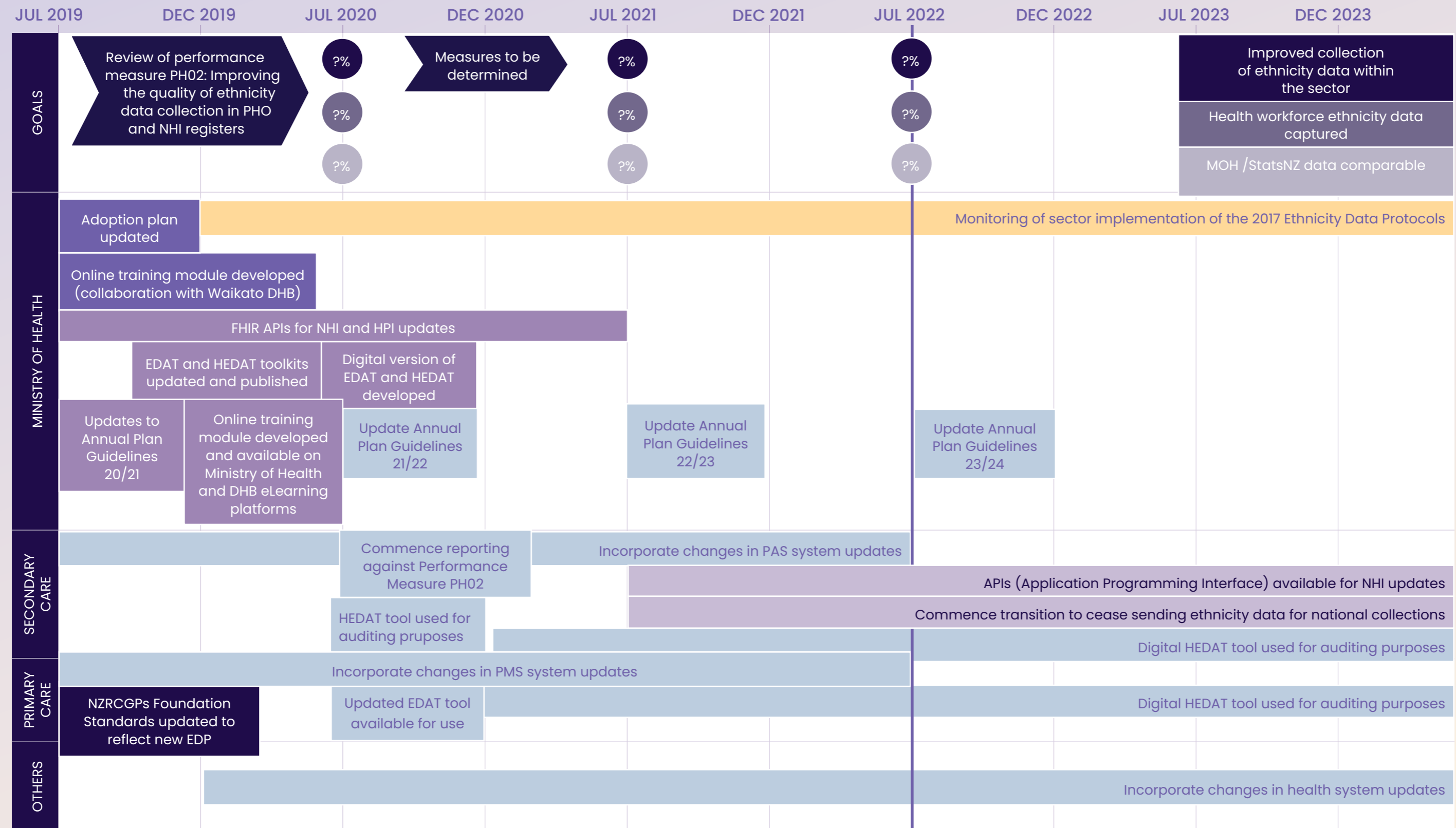
- ✓ -None-
- NZ Māori
- NZ European
- African
- Chinese
- Cook Island Māori
- Fijian
- Indian
- Latin / Hispanic
- Middle Eastern
- Niuean
- Other Asian
- Other European
- Other Pacific Island
- Samoan
- South East Asian
- Tongan
- Tokelauan
- Declined to state

## Appendix 2: Ethnicity Data Protocols Adoption Roadmap

Business Owner: Data and Digital

Other contributors: Health System improvement and innovation

### Ethnicity Data Protocols Adoption Roadmap (WORKING DRAFT)



Source: Te Whatu Ora 2022 (previously in Manatū Hauora)



*Ka puta ai te ihu ki Rangiātea.*

*So, that your nose may arrive  
at Rangiātea.*



