Considerations for Māori Data Analyses

A report for Te Aka Whai Ora

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Abbreviations

ACC	Accident Compensation Corporation
APC	Experimental Administrative Population Census
ASH	Ambulatory Sensitive Hospitalisations
CVD	Cardiovascular Disease
COVID-19	Coronavirus Disease of 2019
DHB	District Health Board
ERP	Estimated Resident Population
HISO	Health Information Standards Organisation
HQSC	Health Quality and Safety Commission
HSU	Health Service User
IDI	Integrated Data Infrastructure
IHD	Ischaemic Heart Disease
IMPB	Iwi Māori Partnership Boards
MCNZ	Medical Council of New Zealand
NCNZ	Nursing Council of New Zealand
NHI	National Health Index
NMDS	National Minimum Dataset (Hospital events)
NZHS	New Zealand Health Survey
PAH	Potentially Avoidable Hospitalisations
PHARMs	Pharmaceutical Collection
PHO	Primary Health Organisation
PRIMHD	Program for the Integration of Mental Health Data
SES	Socioeconomic status

Introduction & purpose

This paper seeks to clarify Te Aka Whai Ora's positioning on the issues that should be considered by the organisation and its key health stakeholders, when undertaking or assessing quantitative data analyses associated with Māori health and health inequities. This report focuses on quantitative data analysis of national datasets, but there will be instances where the best approach or methods will be different e.g., qualitative studies, quantitative at the local level, independent research projects.

The report was written in response to various requests for advice or endorsement regarding measuring and monitoring Māori health and inequities. It aims to provide Te Aka Whai Ora and their key stakeholders with guidance on methods that are grounded in underlying research principles and Te Tiriti o Waitangi. The structure of the report, therefore, begins with a description of the principles that inform the authors' positioning. These are then woven throughout the report in relation to specific examples for examining Māori health and inequities. An overview of the importance of understanding ethnicity and ethnicity data are described. This is followed by a description of key considerations related to Māori health data analyses. This covers questions relevant to monitoring Māori health, methods and approaches to measuring Māori health and inequity, and a description of key population statistics and selected datasets, including their strengths and limitations. While the intended audience is Te Aka Whai Ora and key stakeholders, the report may be useful to other groups looking to undertake data analyses by ethnicity.

This report has been informed by Māori (and non-Māori) public health and Kaupapa Māori epidemiological expertise. The content reflects extensive experience within research, policy and strategy settings with authors who have been associated with ethnicity data theorisation and analysis both within Aotearoa New Zealand and internationally. The content of this paper should be read in conjunction with the report prepared for Te Aka Whai Ora, "Action plan for achieving high quality ethnicity data in the health and disability sector" (McLeod & Harris, 2023).

Underlying principles

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 & McLeod, 2010). Achieving high quality ethnicity data must be an urgent priority for the whole health system.

In addition to high quality ethnicity data *collection*, is the need to ensure high quality ethnicity data *analysis* occurs across the health sector. This requires a clear understanding of the purpose of any analyses, and a comprehensive understanding of the strengths and limitations (or risks and benefits) associated with different datasets, denominators and comparators available for quantitative data analysis within an Aotearoa New Zealand context.

However, how you determine risk and benefit will be influenced by the values and principles that underlie your positioning and approach to Māori health data analysis, including your understanding of drivers of health and health inequity. In addition to the right to health, Māori health and inequities are also situated within the broader context of Māori Indigenous rights and Crown

responsibilities to ensure these rights. The authors of this paper acknowledge the underlying principles that inform their positioning (Paine et al. 2020; Robson and Harris 2007; Curtis 2016). These include:

- *Māori have the right to be counted (and therefore valued).*

This reflects Māori Indigenous rights as tangata whenua of Aotearoa New Zealand and Māori equity needs given the disparities experienced by Māori across multiple domains within society. In order to be counted, high quality ethnicity data needs to be collected, analysed and reported on appropriately.

- *Māori have the right to monitor the Crown.*

The ability to monitor the Crown effectively (and over time) aligns with commitments articulated within Te Tiriti o Waitangi and the UN Declaration on the Rights of Indigenous Peoples (Te Tiriti o Waitangi, 1840; UN General Assembly, 2007). The Crown has a responsibility to ensure that Māori health needs and priorities are addressed, and Māori health outcomes are enhanced and protected across society. This responsibility requires the collection of high quality ethnicity data alongside the production of high quality ethnicity data analysis and interpretation in order to assess the performance of the Crown appropriately.

- *Māori have Indigenous rights as tangata whenua to be a priority within ethnicity data analyses.*

As noted above, Māori Indigenous rights as tangata whenua of Aotearoa New Zealand are reaffirmed by Te Tiriti o Waitangi and articulated within other international agreements. This positioning supports Māori being prioritised within ethnicity data collection and approaches to ethnicity data analyses within an Aotearoa New Zealand context. Treating Māori ethnicity data issues to be the same as "other ethnic minorities" (or playing the priority of ethnic groups off against one another) fails to acknowledge Māori Indigenous rights and is therefore not Te Tiriti o Waitangi compliant.

- *Māori rights to mana motuhake (self-determination) require Indigenous Data Sovereignty principles to be upheld.*

Indigenous data sovereignty (Te Mana Raraunga, 2018) recognises that Māori data should be subject to Māori governance in order to support tribal sovereignty and the realisation of Māori and Iwi aspirations. Professor Tahu Kukutai describes Indigenous data sovereignty as being required to put "Indigenous data in Indigenous hands for Indigenous benefit" (https://www.youtube.com/watch?v=Q4e7hu6QjKg). How we promote Indigenous Data Sovereignty principles with respect to ethnicity data collection and management remains an important challenge to be considered.

- *The Crown requires high quality ethnicity data and analyses for Māori to uphold its obligations under Te Tiriti o Waitangi.*

The Crown has an obligation to ensure Māori receive equitable benefits of citizenship and protection of 'taonga katoa' as guaranteed under Te Tiriti o Waitangi. Pae Ora (Healthy Futures)

Act 2022 gives effect to the principles of Te Tiriti o Waitangi, and Te Pae Tata (Interim NZ Health Plan) "embeds Te Tiriti o Waitangi as its foundation, sharing decision-making and resources and making the whole health system accountable for Māori health equity" (Te Whatu Ora, n.d.). It is not possible for the Crown to achieve this unless it is informed by an accurate assessment of Māori needs and outcomes. High quality ethnicity data collection and analysis are essential to achieve this.

- *Values and positioning should be framed to support equity and Māori Indigenous rights.*

All quantitative data analysis has a theoretical positioning and values base. Fundamental questions about what data are included, and how they are analysed and interpreted, are determined by the values and understandings of Māori health equity of those planning and undertaking any analyses. Researchers and policy makers should be explicit about their values and align themselves with approaches that support the realisation of equity and Indigenous rights for Māori. This may include organisational positioning, specifically of Crown health entities, that may not necessarily align with individual Māori staff within the organisation. It is important to understand and acknowledge current Māori health within a context of racism and colonisation (Reid et al., 2019) and interpret data within this context.

1. What is ethnicity?

How is ethnicity defined in the health and disability sector?

Ethnicity is a social construct that reflects the processes that drive differences in social outcomes (Williams & Mohammed, 2013). It is not a measure of biological (e.g., genetic) differences (Cormack, 2010), but is a marker of social perception/treatment which influences people's experiences and outcomes. Therefore, ethnicity is particularly relevant to the understanding and measurement of health and health equity, given that the major 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 & Harris, 2007). Self-identification as a key component of ethnicity, aligns with principles of self-determination and the right for Māori to name themselves as Māori (Robson & Reid, 2001; Te Rōpū Rangahau Hauora a Eru Pōmare, 2000).

Statistics 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 (StatsNZ, n.d.). This Statistical Standard for ethnicity is under review. The NZ health sector has ethnicity data protocols (called Ethnicity Data Protocols: HISO 10001:2017) for the collection, recording and reporting of ethnicity data, that are based upon the StatsNZ ethnicity standard (Ministry of Health, 2017). The users identified in the protocol include those collecting data, using data, and health information software developers. Agencies such as Te Whatu Ora, Manatū Hauora and Te Aka Whai Ora are both collectors (e.g., workforce data, health surveys) and users of ethnicity data.

> "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, 2017. HISO 10001:2017 Ethnicity Data Protocols

How are ethnicity data used in health?

Ethnicity data are used in many ways across the health system. For example:

1. to make sure that enough **funding** is allocated to address Māori health needs,

2. to identify Māori individuals for the delivery of **targeted health services** such as, cardiovascular risk assessments and bowel screening at an (appropriately) earlier age,

3. to measure Māori **health needs** and to **monitor the health system's performance** in providing high quality and accessible care for Māori**,**

4. to inform the **prioritisation** and delivery of healthcare resources such as prioritisation criteria or algorithms for access to care (e.g., admission to ICU during the COVID-19 pandemic (Roy et al., 2021) or risk assessment algorithms ([Algorithm Hub](#)), and

5. to monitor and improve **Māori workforce** representation.

This report mainly focusses on issues related to bullet point 3 above, measuring Māori **health needs** and **monitoring the health system's performance** in providing high quality and accessible care for Māori. This report is primarily focussed on national level analysis, but the concepts are equally relevant to monitoring Māori health at a regional or local level, although the availability of data may differ. We also briefly discuss datasets in relation to bullet point 2, identifying Māori individuals for the delivery of **targeted health services**.

The purpose of any analyses (e.g., to determine funding) and the specific questions to be answered should guide any decisions about: the most appropriate data source (considering who is included/excluded in different datasets and the quality of data available), how to group ethnicity data (i.e. ethnicity categorisation), and the selection of a comparator group(s).

2. Ethnicity data collection

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

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 equitable funding, identifying individuals for targeted services, assessing needs, and monitoring ethnic-specific trends and health inequities over time (Te Rōpū Rangahau Hauora a Eru Pōmare, 2000).

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 which is the same as the 2023 Census question presented in Figure 1. Guidance is provided in the protocols for asking this question in different formats e.g., on paper, verbally, online, and by proxy as required.

Figure 1 Standard ethnicity question 2023 census

Deviations from the standard question, including the wording of the question, the categories offered, the order of options, the presence of an opt-out option, and the ability to select multiple ethnicities, can all contribute to changes in how respondents answer the question. Of interest, the 2023 census ethnicity question presented online, had an altered stem question, asking respondents to "select all that apply to you".

Case study: The impact of changing the 1996 Census ethnicity question.

An example of the impacts of changing the ethnicity question (and the importance of using the correct question) comes from changes in the question used in the 1996 census. The 1991 census question was very similar to the one we use today (see Figure 1 above). In contrast, the 1996 question used a different question stem which asked people to "Tick as many circles as you need to show which ethnic group(s) you belong to". In addition, extra categories were added to the list, which mainly consisted of additional European categories (English, Dutch, Scottish, Irish)

Subsequent research has shown that these two changes encouraged multiple ethnic responses. Further, these responses were more likely to be based on ancestry than were responses to the 1991 Census ethnicity question (AC Neilsen, 1999). Consequently, the 1996 "sole Māori" group is significantly smaller than expected and the "Māori ethnic" group larger. It is likely that some who gave a "sole Māori" response to the 1991 question gave an ancestry-based multi-ethnic response to the 1996 question. Furthermore, some people of Māori ancestry who previously had not identified Māori ethnicity, seem to have been encouraged by the 1996 question to add Māori to their ethnicities. These changes in population numbers by ethnicity caused problems in the monitoring of health trends over time (Robson & Reid, 2000).

Improving quality of ethnicity data collection is a responsibility of the whole health sector

Although high quality ethnicity data are critical for Māori health improvement, ethnicity data quality remains poor. 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. 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 & Harris, 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 with differences by age and gender (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 aged 20-24 years, where the NHI misses 30%, or almost one in three Māori (Harris et al., 2022).

StatsNZ review of the ethnicity statistical standard

StatsNZ is currently leading a review of the Ethnicity Standard in 2023. StatsNZ have reported receiving some feedback from the public that they would like to see a broader range of options specified in the ethnicity question (StatsNZ, 2020a).

As noted above, the Ethnicity Standard and question is the basis for ethnicity data collection in the health sector and there must be a very high threshold for changes to the Ethnicity Standard (or the ethnicity question), given the potential impacts on our ability to monitor Māori health and inequities over time. Maintaining the time series is particularly important in the context of recent health reforms and the disruptions to the health sector from COVID-19, and our ability to monitor impacts of these on Māori health and equity.

Robson and Reid (2001, p14) note that: "while the population's knowledge and attitudes towards the measurement of ethnicity may be changing, and this in turn may require some evolvement of the ethnicity question over time, changes ought to be incorporated in a way that disruption to historical continuity is minimized." There have been previous reviews of the Ethnicity Standard with many of the issues raised by Māori remaining relevant in the current review. Changes in the question can lead to marked changes in the size and makeup of the Māori population as well as changes to comparison groups.

> "…a change to the ethnicity question in the 1996 Census led to a significant change in the size and demographic make-up of the Māori ethnic populations. Monitoring trends over time became problematic. For example, if health time trends improved, it was difficult to tease out if there had been a real improvement in Māori health or whether the 'improvement' was an artifact of a larger Māori ethnic group as a result of the changed census question … (Te Rōpū Rangahau Hauora a Eru Pōmare, 2000)." (Robson & Reid 2001, p14).

Given the critical importance of a stable ethnicity question to the ability to monitor Māori outcomes over time, and the disruption caused by any changes to the question, the threshold for changing the question/standard must be very high. Public feedback reflecting different understandings of ethnicity does not necessarily mean that the question needs to be changed. This may signify that

other avenues, such as awareness-raising or public education on ethnicity data is required. Changing the question at this time point, with the need to assess major health reforms and COVID-19 impacts, is especially ill-advised.

Included in the StatsNZ ethnicity standards review scope are ethnicity data processing methods and outputs. It is important for Māori to retain the ability to monitor Māori health, inequities and the Crown, drawing on a range of appropriate methods and ethnicity data categorisations. We would discourage any limitations being set on the methods that Māori are able to use to categorise ethnicity, so we maintain our right to measure and monitor health and health equity in any ways we deem appropriate. This is discussed in more detail in the comparator section on page 19.

3. Ethnicity data analysis
What are the key questions that need to be answered?

The use of health data to inform Māori health needs requires a clear understanding of the purpose of any analysis, and more specifically what questions need to be answered. As discussed above, the questions asked will be influenced by who is asking, and their understandings of Māori health and inequity. Following from this, will be determining the best approaches or methods for answering these questions, including the most appropriate sources of information. As noted above, this report focuses on the analysis of national datasets. We acknowledge that at times the questions and methods (including data sources) may differ when examining health and inequities for other population groups e.g., Pacific.

Choices of data are secondary to and dependent on the questions asked and how these can best be addressed. The nature of the datasets, data quality (including ethnicity data) and availability are important considerations in selecting the best data, including whether a fresh collection of data is needed. Key considerations when selecting appropriate datasets is clarity on who you want to answer questions for e.g., total population or health service users, and the quality of ethnicity data on the datasets e.g., undercounting, and how quality varies across datasets as well as by key variables such as age and gender. The presentation of any Māori health data should include information on the data source and quality and the impact of these on the presented estimates. Any methods (e.g. adjustments or imputation) to address missing or poor data quality also need to be described.

Key examples of existing reports that measure or monitor Māori health include the Hauora series (e.g., Robson & Harris, 2007), Māori Health Chartbooks (e.g., Ministry of Health, 2010; 2015), DHB Māori health profiles (Te Rōpū Rangahau Hauora a Eru Pōmare, 2015), Wai2575 Māori Health Trends report (Ministry of Health, 2019). The following sections of this report consider some of the key questions, data sources and analytical approaches in measuring and monitoring Māori health and inequities. The sections are:

1. Measuring Māori health status and health needs (without comparing to another population group). This includes describing the Māori population, understanding the determinants of health (including monitoring health service performance), and measures of health need (such as disease rates, mortality). This allows the identification of Māori health priorities based upon need within the Māori population. These measures can occur at a single point in time or be measured over time.
2. Measuring ethnic inequities in the above measures for Māori compared to other groups (one-off & over time).
3. Using existing datasets to find Māori individuals for targeted services.

Measuring Māori heath status & need

When measuring Māori health, there is a need to engage with a range of questions and data from a wide range of sources. In this report, we have focussed on national data collections and many of the

examples focus on the total Māori population. However, the methods discussed are also applicable when focussing on specific groups of interest e.g. children, older people, women, geographic location. There will also be other sources of data such as local surveys and registers that are not covered in this report. Additionally, some questions are better answered with qualitative data and by engaging directly with Māori (e.g., individuals, whānau, communities, hapū, iwi). Regardless of the source of data, it is important to understand the reach of the dataset (i.e., who is included and who is not) as well as the quality of the data within the dataset (including ethnicity and health data).

Understanding Māori health and health needs requires examination of a range of information. This includes the **number of Māori in the population** (e.g. total, regional, local) and their demographic characteristics (e.g., age and gender). These data are usually derived from official population data from Stats NZ such as population censuses, estimated resident populations (ERP), and population projections (see page 26 onwards for a brief description of these datasets). These data try to capture the entire NZ population, including the Māori population (based on ethnicity). A range of methods are used to try and achieve a complete capture of the population e.g., ERP is based on numbers from the associated Census adjusted for migration, births and deaths, and missing data. It is important to understand the limitations of all datasets although ERP is currently the best estimate of the Māori population. In the context of planning, Māori population projections are important and available from Stats NZ.

Māori health is also driven by **wider determinants of health** such as education, income, employment, deprivation, incarceration, and racism. Common sources of data for socioeconomic measures will come from Stats NZ and other government agencies e.g., Ministry of Education. Experiences of racism are collected within national surveys such as the New Zealand Health Survey, the General Social Survey, and Te Kupenga. From a Māori perspective, differing patterns of socioeconomic determinants of health can be interpreted as a result of colonisation and racism (Reid et al., 2019), with ethnic inequities in these measures considered markers of institutionalised racism (Nazroo, 2022). Measures such as whānau wellbeing and access to Te Ao Māori e.g., Te reo, may also be considered and are available from sources such as the General Social Survey, Te Kupenga, the Census and other surveys.

Measures of health service performance such as **health service access and quality** are also determinants of health. A number of national datasets allow the examination of health service use for example, PHO enrolments, NMDS hospitalisations, Cancer registry, PHARMs (pharmaceuticals), PRIMHD (mental health), Notifiable diseases (Episurv), Immunisation and Screening registers. Health workforce composition data is also available from a range of sources e.g., MCNZ, NCNZ. For Māori, measures of health service use can be compared to targets (e.g., coverage targets for immunisations and screening). The ability to meet service targets (including levels of coverage, service guidelines and national expectations for timeliness of care) for Māori will be affected by the availability and supply (e.g. capacity, volumes, funding) of these services (for example across regions), and therefore lower coverage of services should be interpreted in this context, and not just as a difference in levels of engagement or underlying Māori health need between regions. When looking at measures of health services, it is also important to consider them in the context of Māori health needs. Sometimes this requires an examination of inequities across the continuum of care for Māori compared to other ethnic groupings. This approach is discussed further on page 22.

Important composite measures using hospitalisation data are Ambulatory Sensitive Hospitalisations (ASH) and Potentially Avoidable Hospitalisations (PAH). ASH includes hospitalisations that could be avoided with good access to primary care and appropriate management. They are a subset of the broader category of PAH which additionally includes hospitalisations that could be avoided through broader actions and policies that improve wider determinants of health, including injury prevention (Anderson et al., 2012; Ministry of Health, 2010; Ministry of Health, 2020a). Similarly, two composite measures using death data are amenable mortality and preventable mortality (together comprising avoidable mortality). Amenable mortality includes deaths among those under 75 years that could have been avoided with timely access to high quality healthcare available within New Zealand (Ministry of Health, 2018a). Preventable mortality includes deaths under the age of 75 years that could have been avoided through primary prevention that addresses determinants of health, and health care (Walsh & Grey, 2019). For Māori, examining trends in these measures over time provides an important indicator of health system and wider government performance in efforts to improve Māori health.

There are also several healthcare measures that are not captured by administrative health datasets, including patient reported unmet need and patient satisfaction that are instead captured in other data sources such as the NZHS and HQSC surveys. Healthcare satisfaction and measures of experience with healthcare provide useful information for service improvements. However, these measures should always be interpreted in the context of how health services are performing for Māori in relation to equity and outcomes, and with consideration of the quality of the surveys to examine Māori experiences (e.g., sampling methods and study power).

Māori health status can be described in a wide range of different ways. At the broadest level, there are some **"global" measures of health** such as life expectancy, population mortality rates, and a range of other measures that capture both the quantity and quality of remaining life (e.g., Health-adjusted life expectancy and Years of life lost). These are critical indicators to monitor for progress towards reducing inequities. They provide a picture of the overall progress towards health across all diseases and encompass the impact of both health care and determinants of health. Life expectancy and population mortality rates are available from StatsNZ life tables. Information on the other indicators are less readily available and often derived from the Global Burden of Disease study, NZ data (Ministry of Health, 2020b).

Māori health need is commonly measured for **specific diseases** such as cardiovascular disease, cancer, diabetes, mental health etc. Important questions may include:

- How common are different diseases for Māori?
- At what level of disease (e.g., stage) are Māori being diagnosed?
- Which diseases cause the most deaths in Māori?
- How do the above vary by age group, gender, region, SES?
- How are these changing over time?

The ability to get accurate measures of individual diseases is in part dependent on the availability and quality of data as well as access to healthcare in order to be diagnosed and registered as a case. For example, cancer registrations data are usually used to present the number of, and rates of new

cancers diagnosed. Most people with cancer will present to healthcare at some stage, and therefore most people with cancer (excluding some skin cancers) are expected to be in the Cancer Registry data. In contrast, healthcare data may not capture the full range of mental health conditions well. For example, those with more severe mental health conditions are more likely to present to health services (than those with less severe mental health conditions); or services available may be limited. This is particularly an issue for Māori who face greater barriers in accessing health services.

Methods for measuring Māori health, healthcare access and quality

There are a number of key measures to consider in describing Māori health and healthcare quantitatively. These include numbers, proportions, and rates which may be associated with specific terms in epidemiology. For example, the numbers (frequency) and proportions of people with a disease (prevalence), newly developing a disease (incidence), or dying from it (mortality). These measures can be presented for the Māori population overall, as well as by age and gender groupings to reflect the differing patterns of disease within the Māori population. In addition, these same measures can be compared to another population group(s) to assess progress on eliminating ethnic inequities in health and healthcare.

Numbers, proportions and crude rates

It is common to see health data for Māori presented as rates that have been age-standardised (or adjusted) and compared to other ethnic groups. However, simple measures such as the number of Māori with a particular condition, proportions, and rates without age-adjustment (crude proportions/rates) allow us to answer simple questions such as "which diseases are the most common for Māori?" or "which diseases cause the greatest numbers of deaths for Māori?"

Figure 2 provides an example of this type of analysis. This is taken from *Hauora IV: Māori Standards of Health* (Robson & Harris, 2007), and while based on older data is a useful way of presenting rankings of the a) most common cancer registrations and b) the greatest number of cancer deaths for Māori. For example, lung and female breast cancer are the two most common cancers for Māori and also cause the greatest number of cancer deaths. For the other cancers, the order of ranking varies for registrations (diagnoses) compared to deaths. The rankings of different cancers could also be examined by age group and are likely to be different. It is important to note that mortality reflects the combination of how common a disease is along with survival from the disease; for example, there are high numbers of lung cancers which is part of the reason why there are high numbers of deaths from lung cancer. To measure the risk of death for people that have a particular disease, disease-specific survival and case-fatality rates can be used. Using the example below, pancreatic cancer is less common than some other cancers (ranked 10), but has poor survival so is ranked higher among deaths (at 7). While this figure uses numbers and percentages to rank the cancers, crude rates could also be used and in this example would show the same rankings. Additional methods may be required when comparing Māori to other population groups with differing age structures (e.g. age specific and age standardised rates). These are discussed on page 23.

Figure 2 Example of Māori rankings for a) cancer registrations and b) cancer deaths

a) Cancer registrations

Māori			Rank
Site	Number	% of new cases	
Total (both sexes)			
Lung	1,366	20.4	1
Female breast	1,069	16.0	2
Prostate	606	9.8	3
Colorectal	469	7.0	4
Stomach	288	4.3	5
Leukaemias	244	3.6	6
Non-Hodgkin's lymphoma	201	3.0	7
Liver	186	2.8	8
Cervix uteri	174	2.6	9
Pancreas	149	2.2	10

b) Cancer deaths

Māori			Rank
Site	Number	% of cancer deaths	
Total (both sexes)			
Lung	1,127	31.4	1
Breast: female	344	9.6	2
Colorectal	254	7.1	3
Stomach	213	5.9	4
Prostate	153	4.3	5
Liver	141	3.9	6
Pancreas	128	3.6	7
Non-Hodgkin's lymphoma	105	2.9	8
Leukaemias	94	2.6	9
Oesophagus	81	2.3	10

Source: Robson & Harris, 2007

Stratification of Māori data by other factors

In addition to understanding which diseases occur most commonly or cause the greatest number of deaths for Māori overall, it is also important to examine patterns of health and healthcare use within the Māori population by factors such as age, gender, location, and deprivation. This approach is called stratification and provides information to better understand who is being affected by conditions or using services (and who is not), and to allow the prioritisation of Māori with the greatest needs. Figure 3 is taken from *Hauora IV: Māori Standards of Health* (Robson & Harris, 2007) and shows public hospitalisation rates for Māori (and non-Māori) by both age and gender with the highest rates for Māori (and non-Māori) occurring in males and females under the age of 1 year. In Figure 3, the higher rate of hospitalisations for Māori under the age of one is expected, due to births being counted as hospitalisations, showing the importance of taking account of the context of the numbers presented.

Figure 3 Example of Māori data stratified by age and gender (Source: Hauora IV)

All-cause public hospitalisations

Table 5.1:   Public hospitalisation rates by sex and age group, 2003–2005

Age group	Female			Male		
	Māori rate	Non-Māori rate	Rate ratio	Māori rate	Non-Māori rate	Rate ratio
All ages	25,915.2	19,803.0	1.31	20,968.7	15,761.0	1.33
Under 1 year	125,380.2	157,187.7	0.80	135,865.6	165,460.1	0.82
1–4 years	15,700.1	14,766.3	1.06	19,463.4	18,738.8	1.04
5–14 years	7,338.2	6,918.0	1.06	8,992.6	8,218.1	1.09
15–24 years	29,151.3	16,195.6	1.80	10,599.5	8,161.1	1.30
25–44 years	27,376.4	22,407.4	1.22	13,803.0	9,111.4	1.51
45–64 years	30,292.2	14,690.6	2.06	34,504.1	15,847.3	2.18
65 years and over	63,029.5	35,555.2	1.77	82,474.7	44,974.1	1.83

Notes: Rates are calculated per 100,000; rates for 'all ages' and 65 years and over were age-standardised to the 2001 Māori population; shaded rate ratios are statistically significant at the 5% level.

Source: Robson & Harris, 2007

In-depth analysis of health data for particular groups of interest within the Māori population may also be required at times. This may use data *restricted* to specific parts of the life course. (e.g. tamariki, rangatahi, pakeke, kaumātua) or by region (e.g. iwi, localities). Tatau Kura Tangata (Ministry of Health 2011) and Te Ohonga Ake (Simpson et al. 2017) are examples of analyses restricted to specifc age groups. Again, data limitations in relation to data availability and data quality should be understood and articulated for these groups. For example, ethnicity data quality varies by age and gender (Harris et al. 2022). There are also important groups such as tāngata whaikaha, gender diverse populations, and people who are experiencing homelessness or incarceration where data are currently limited in being able to adequately provide information to inform their health needs.

Age standardisation and trends over time

In addition to understanding which diseases are the most common or have the highest mortality at a single point in time, it is useful to look at trends over time. The Māori population is ageing over time, increasing the numbers and proportions of Māori in older population groups. This will in turn mean that diseases that occur in these older age groups will become more common. To assess whether there is a greater risk of a disease over time, it is necessary to remove the effect of the ageing population from the analysis. This can be done with a method called age-standardisation which produces rates that assume that the population has the same age pattern at each point in time. These rates are usually not the real rates of disease but are created to allow comparisons over time by removing the effect of population ageing (i.e., removing confounding by age). A range of standard populations are available for age standardisation. The Māori 2001 population standard has been used for a number of years which has allowed the monitoring of Māori health and inequities over the last two decades. The 2001 Māori standard has previously been recommended by Māori researchers (Robson et al., 2007) and supported by Manatū Hauora (Ministry of Health, 2018b), and was used in time series analyses in the WAI2575 claim (Ministry of Health, 2019). Age standardising to an Indigenous standard has been suggested internationally as better reflecting indigenous realities (Thurber et al., 2022). As the Māori population ages, the 2001 standard becomes less representative of the current Māori population. However, calls to update the Māori standard must be balanced against the impact of interrupting the time series and/or the capacity to retrospectively apply a more recent Māori standard. Given recent health system reforms and the impacts of COVID-19, maintaining a time series by continuing to use the 2001 Māori population standard (alone or in combination with an updated standard) is important. Age-standardisation is further discussed in the context of comparing population groups (e.g., Māori compared to sole European) with different age structures on page 23.

Measuring inequities (determinants, outcomes, healthcare access & quality)

> "Māori seek to remove ethnic disparities, not to become Pākehā, but as an expression of full citizenship in Aotearoa." (Reid et al., 2000, p45)

In addition to measuring health need within the Māori population, all of the above dimensions of Māori health status can be used to assess inequities, by directly comparing to another population group. The measurement of inequities in epidemiology, particularly the comparison of Māori compared to Pākehā, has been criticized as implying that Māori should be seeking to achieve a Pākehā standard (Paine et al., 2020). We would argue that monitoring inequities is important for monitoring Māori rights. Māori have the right to good governance and equity in health and other areas. Monitoring inequities does not mean that Māori seek to aspire to Pākehā norms but rather, the monitoring of inequities provides important information in understanding whether Māori rights to health are being met and indicates the responsiveness of the health system and wider government to address Māori health needs as a right (Paine et al., 2020). Additionally, an interpretation and understanding of inequities as driven by systems and structures that in Aotearoa are rooted in colonialism and racism, shifts the focus away from blaming Māori for poor health to highlighting the role of systems in generating disadvantage and privilege. It is important that Crown health agencies understand and acknowledge colonialism and racism as the basic causes of Māori health inequities in causal frameworks, and as such, address Māori health and health inequities as a priority.

Comparators

As with many variables in epidemiology, there are a range of methods for grouping (i.e., categorising) ethnicity data. In health, standard outputs related to aggregating ethnic groups are prioritised, total response and sole/combination (Ministry of Health, 2017). Sole/combination is referred to as single/combination by StatsNZ (StatsNZ 2022c). The selection of categorisation depends upon the question(s) to be answered, with the most common categorisations in health being prioritised and total response. For the Māori ethnic group, prioritised ethnicity and total response Māori will give the same number of people (as Māori are prioritised first). In relation to Crown obligations to monitor inequities it would be unusual to use sole/combination categorisation for Māori as Crown obligations to Māori do not differ by these categories; Māori have the same rights regardless of whether they only identify as Māori, or with a number of ethnic groups in addition to Māori. These three different categorisations are often treated as independent from one another, but in monitoring Māori health it may be appropriate to draw across these categorisations. For example, in an analysis where one wants to examine healthcare privilege, a prioritised (or total response) Māori group may be selected and compared to sole European (as the most socially privileged group) which comes from a sole combination approach. As such, in ongoing reviews of ethnicity data in NZ, we would discourage any limitations being set on the methods that Māori are able to use to categorise ethnicity, so we maintain our right to measure and monitor health and health equity in any ways we deem appropriate.

The choice of ethnicity categorisation is important for Māori particularly with respect to the selection of comparator groups. In selecting appropriate comparator groups for understanding Māori health equity, we need to:

1. have clear rationale for the comparator group selected, including in relation to Te Tiriti o Waitangi,

2. select a comparator group that does not overlap with Māori (i.e., is mutually exclusive),

3. understand who is represented in the comparator group, and how this may impact on measured inequities, and

4. understand data quality limitations (including misclassification of ethnicity and missing data) and potential impacts on measured inequities.

Here we consider two main approaches to selecting a comparator group for measuring Māori health equity. The first is a Māori/non-Māori analysis. This is a common approach to measuring Māori health equity. Paine et al. (2020) note that, "The use of Māori/non-Māori analyses acknowledged the fundamental nature of our relationship with the Crown affirmed in Te Tiriti o Waitangi"(Paine et al., 2020, p193). Additionally, a Māori/non-Māori analysis is often the more straightforward practically in the context of data quality and statistical power limitations and provides a non-overlapping comparison group. The limitations of this approach relate to difficulty in conceptualising non-Māori as a group which includes a number of different ethnic groups. Also, Māori/non-Māori comparisons will often underestimate inequities between Māori and NZ European in part because of the inclusion of Pacific in the non-Māori group (who more often have similar health and socioeconomic experiences to Māori). The quality of ethnicity data, especially for Māori in some NZ health datasets will mean that a Māori/non-Māori approach will have a number of Māori incorrectly included in the non-Māori group (misclassified as non-Māori). The impacts of this misclassification of ethnicity on measures of health and inequity should be considered.

The second approach is particularly relevant in the context of examining patterns of health and health equity for multiple ethnic groups. A sole European (or sole NZ European) ethnic group comparator which includes those individuals that identify their ethnic group or groups as European only (acknowledging that the broader European category is also comprised of a range of European ethnicities) or NZ European only is useful for comparing Māori (and Pacific) to the most socially privileged population (also consistent with a Te Tiriti approach in relation to power and equity). In contrast to a Māori/non-Māori comparison, it is relatively clear who is represented in the sole European comparator group. To be clear, a sole European comparator group differs from a total European comparator, the latter of which is problematic when estimating ethnic inequities as it will contain a number of Māori and other non-European groups. Ethnicity data quality, availability, and statistical power can require a variation on this privilege analysis, for example when data cannot be disaggregated to sole European. This may include alternative comparison groups such as the combined European and other, or non-Māori non-Pacific. As above, when these comparison groups are used it is important to understand their ethnic composition and impacts on measures of health and inequity.

Comparator groups should <u>not</u> be overlapping. The total European or total NZ populations are inappropriate comparators, because of the large overlap with the Māori group, and the subsequent underestimate of any inequities. 54% of the total Māori population also identify with another ethnic

group in addition to Māori (StatsNZ, 2018). As discussed above, the total response categorisation may be useful (especially for Pacific and Asian groupings), however this also requires a non-overlapping comparator group in the examination of inequities. It is important to note that the total response categorisation applies to both the numerator and denominator, so while precision of estimates may be increased for Pacific and Asian groupings, rates may not necessarily be impacted. An example of this type of analysis is Manatū Hauora's report on experiences of racism from the NZHS which uses a non-Māori non-Pacific non-Asian (i.e. largely European) mutually exclusive comparator (Ministry of Health 2023). Understanding who is represented in the selected comparator group also applies when examining inequities for groups other than Māori (e.g., Pacific, Asian). For this reason, we do not advocate for the routine use of Pacific/non-Pacific, Asian/non-Asian comparisons for assessing health equity.
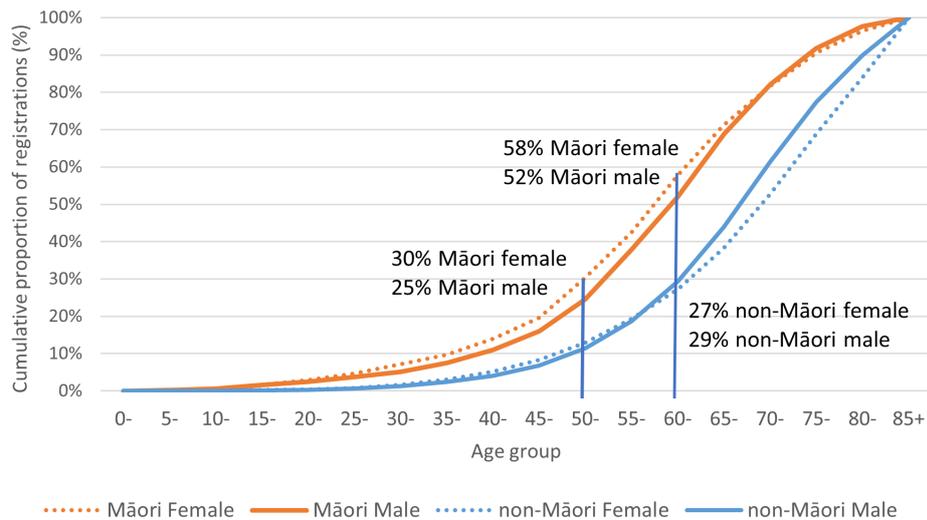
Measures of inequity

In addition to understanding Māori health need within the Māori population, it is also important to understand privilege and inequities in health to monitor Crown obligations to Māori and to identify areas for action. This requires Māori health statistics to be compared to another group (as described above). This can be a comparison of numbers, proportions, and rates. For ease of explanation, we discuss inequities in relation to non-Māori in the rest of this section using examples. The issues outlined also apply to other comparison groups e.g., sole European, non-Māori non-Pacific.

Example 1 – Comparing numbers and proportions – Bowel cancer screening age extension

Figure 4 shows the percentage of bowel cancers being diagnosed before each age group for Māori compared to non-Māori. The national bowel screening programme (NBSP) originally invited New Zealanders between 60-74 yrs. This graph shows that 58% of bowel cancers in Māori females are diagnosed before the age of 60 years compared to only 27% in non-Māori females showing that the original screening age range was inequitable for Māori (as it was missing a larger proportion of bowel cancers for Māori than non-Māori). In 2022, the NBSP extended the age of eligibility for Māori and Pacific down to 50 years. This is the age at which the proportion of bowel cancers among Māori were similar to non-Māori at age 60 years (McLeod et al., 2021).

Figure 4: Bowel Cancer proportions by age and ethnicity

Source: McLeod et al., 2021

Example 2 – Comparing rates: Absolute and relative measures of inequity in CVD and ARF

Using age-specific or age-standardised rates, inequities can be measured in absolute and relative terms. Both are important as they provide different information. For example, CVD is a common disease with large absolute and relative inequities in hospitalisations (which are often used as a proxy for incidence and prevalence) between Māori and non-Māori. In 2014/16 the rate of CVD hospitalisations in Māori males was 3285 per 100,000 compared to the non-Māori male rate of 2082 per 100,000. This means that Māori males were 1.58 times as likely to have CVD hospitalisations than non-Māori males, and with an additional 1203 cases of CVD hospitalisation per 100,000 population (absolute inequity) (Ministry of Health, 2019). In contrast, Acute Rheumatic Fever (ARF) is a far less common disease (rate for Māori 8.2 per 100,000 in Auckland 2020, compared with 0.1 per 100,000 for European/Other), with extremely large relative inequities with Māori being 82 times as likely as European/other to have ARF (RR 82 for Māori than European/Other) but smaller absolute inequities (8.1 per 100,000) because it is uncommon (Te Whatu Ora, 2023). Therefore, both could be considered Māori health priorities.

Example 3 – Comparing Health Service Access and Quality of Care in IHD

While healthcare use statistics can be measured at a single point e.g., hospitalisations, procedure rates, immunisation coverage, it is important that they are interpreted in the context of Māori health needs, and inequities across the continuum of care, with rates and inequities examined across the care pathway. Alternatively, Māori healthcare inequities can be examined by following diagnosed individuals through the care continuum (e.g., Hill et al., 2010; McLeod et al., 2010). When looking across the care pathway it is important to examine care for the same population, and where possible for the same time period and using the same denominator.

Table 1 below presents data on IHD mortality, hospitalisations, and revascularisation procedures from Tatau Kahukura 2nd Edition (Ministry of Health, 2010). It shows that while Māori have a similar rate of revascularisation procedures to non-Māori (RR = 1.08, 95% CI 0.98 – 1.18), this is an inequity

in healthcare access in the context of a much higher mortality rates (RR = 2.51), and higher rate of hospitalisations for IHD (RR = 1.50) in Māori.

Table 1 IHD indicators rates* and ratios across the care pathway, for Māori and non-Māori aged 35+ years

IHD indicators	Māori rate	Non-Māori rate	Ratio of Māori to non-Māori rates
IHD mortality, 2004-2006	238.3	95.1	2.51 (95% CI 2.37-2.65)
IHD hospitalisations, 2006-2008	1392.6	928.5	1.50 (95% CI 1.45 – 1.55)
IHD procedures (CABG and angioplasty), 2006-2008.	189.9	176.5	1.08 (95% CI 0.98 – 1.18)

*Rates per 100,000 population are age-standardised to the 2001 Māori census population.
Source: Ministry of Health, 2010.

Comparisons of service use over time need to take account of the context of long-term inequities in access to care. For example, monitoring of changes in service use over COVID-19 pandemic often compares levels of current use to pre-pandemic baseline data (Te Aho o Te Kahu, n.d.; HQSC, 2021). These analyses risk being interpreted with the assumption that the levels of care provided previously (e.g., 2018/19) are appropriate and are the levels we should aim for on an ongoing basis. However, even if Māori achieve that same level of healthcare use today as pre-pandemic, we know that this will often represent underservicing of Māori health need. Also, similar reductions in healthcare provision for Māori may have larger impacts given differences in the stage and severity at presentation.
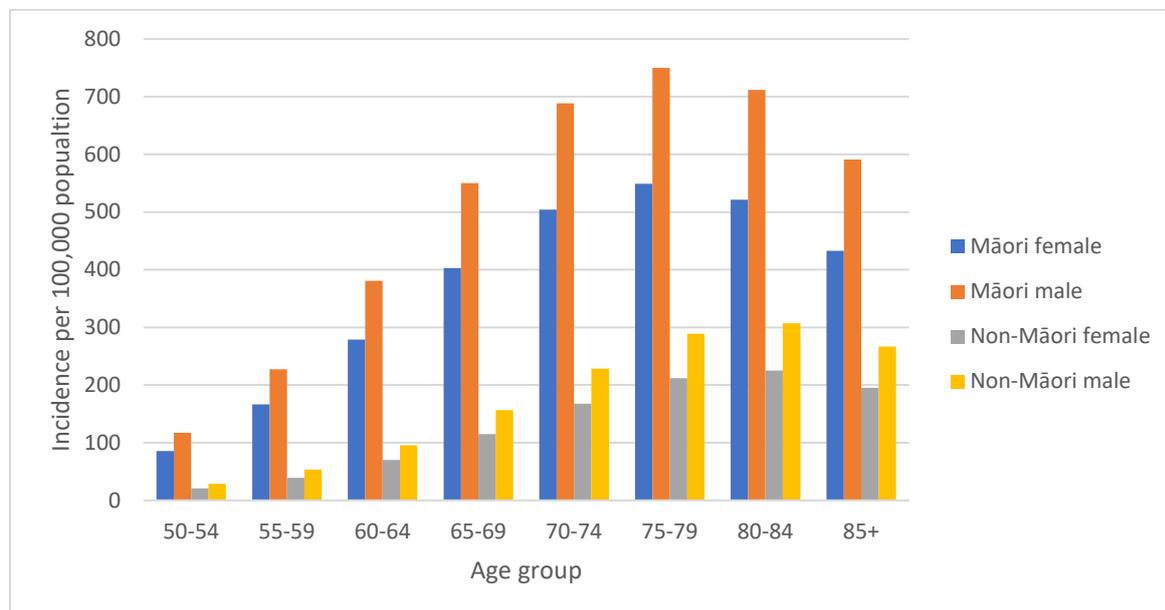
Age-standardisation for comparing population groups with differing age structures

Māori have a younger population age structure to non-Māori, and this is an important consideration in examining rates and inequities. Because many illnesses are patterned by age, disease counts by age group, age-specific rates and age-standardised rates should be used when making direct comparisons between Māori and other population groups.

Examining rates by age group (age-specific rates) provides information on the risk of disease by age and allow comparisons with non-Māori. Age-specific rates are important as they can separate risk of disease at each age group, from the underlying age structure. For many diseases the average age for the Māori population being diagnosed with a disease will be younger than for non-Māori. This will be due to a combination of the Māori population on average being younger, AND different risks (or rates) of diseases by age. To tease out whether Māori have a higher risk of disease at younger ages, age-specific rates of disease can be examined. An example of age-specific rates for lung cancer incidence is presented in Figure 5 and shows for each age-group Māori have a higher risk (rate) of lung cancer than non-Māori. In addition, there is a higher risk of lung cancer in males than in females, for both Māori and non-Māori. Within this graph the age-group with the highest risk is 70-75 years for Māori, compared to 80-84 years for non-Māori, confirming that Māori have a higher risk of lung cancer at a younger age. In addition, Māori are diagnosed at a later stage of disease than

non-Māori. Therefore, the difference in peak incidence would be wider if Māori lung cancers were diagnosed at the same stage as non-Māori.

Figure 5 Lung cancer incidence per 100,000 population, for Māori and non-Māori by age group and gender, 2018

Source: Ministry of Health, cancer registrations

Age-standardisation is useful when comparing overall rates in populations with different underlying age structures, for example when comparing Māori rates to those of non-Māori (as well as examining trends over time as described above). A similar method of age-sex standardisation can be used to adjust for population differences in age and sex or gender (e.g. Robson and Harris 2007). A range of standard populations are available for age-standardisation. Using the 2001 Māori population standard for measuring Māori health and inequities is recommended as it allows comparison to earlier rates that have used this standard, and conceptually aligns with centering Māori realities , as Māori age-standardised rates will be closer to Māori crude rates, although this may change over time as the population ages. Age-standardised rates are often artificial and should only be used to compare rates over time or between populations. In measuring actual health need, numbers and crude rates (including age-specific rates) should be used.

The extent to which the crude rate changes when it is age-standardised depends on how closely the 'standard' used resembles that population in terms of age; standard populations with older age structures will cause large shifts in Māori rates (a relatively young population). In their paper examining the use of different age standards for mortality data, Robson et al. (2007, p1) found that different standards resulted in changes to "rates, rate ratios and rate differences, the relative ranking of causes of death, and the relative width of confidence intervals." This demonstrates the importance of using the same standard over time to measure progress toward health equity for Māori.

Identifying Māori individuals

At an individual level, accurate ethnicity data are also critical to correctly identify individuals eligible for healthcare interventions. "In New Zealand, an individual's ethnicity determines the age of their eligibility for cardiovascular risk assessment and diabetes screening, sore throat management, eligibility for diabetes treatments, and the proposed age extension to the Bowel Cancer Screening Programme." (Harris et al., 2022).

When assessing the quality of ethnicity data held on datasets, it is insufficient to only measure quality at an aggregate level e.g., counting the number of Māori on each dataset to see how closely they match the number on ERP or the Census. In order to be confident that datasets are fit for purpose to identify Māori individuals accurately, these datasets also need to be assessed at the individual level, for example comparing each individual's ethnicity on the dataset to their self-identified ethnicity in the Census or in ethnicity data audits.

Clear documentation of dataset methods, including how ethnicity is sourced and the quality of ethnicity data at the aggregate and individual levels is required in order to understand how the data will perform for both monitoring Māori health and inequities, as well as in identifying individuals for targeted care. This documentation is commonly incomplete or entirely lacking for a number of key datasets in NZ (discussed in dataset section below).

4. Ethnicity in key population statistics and selected datasets

What are the appropriate populations and when?

As discussed earlier, there are multiple ways that ethnicity data may be used, including in funding, monitoring, measuring health workforce, in algorithms and prioritisation criteria and to identify individuals for targeted care. The following section focuses on the relevance of selected population statistics and datasets (herein referred to as "datasets" whilst acknowledging that some of these are population estimates) primarily for measuring and monitoring Māori health and inequities, including over time.
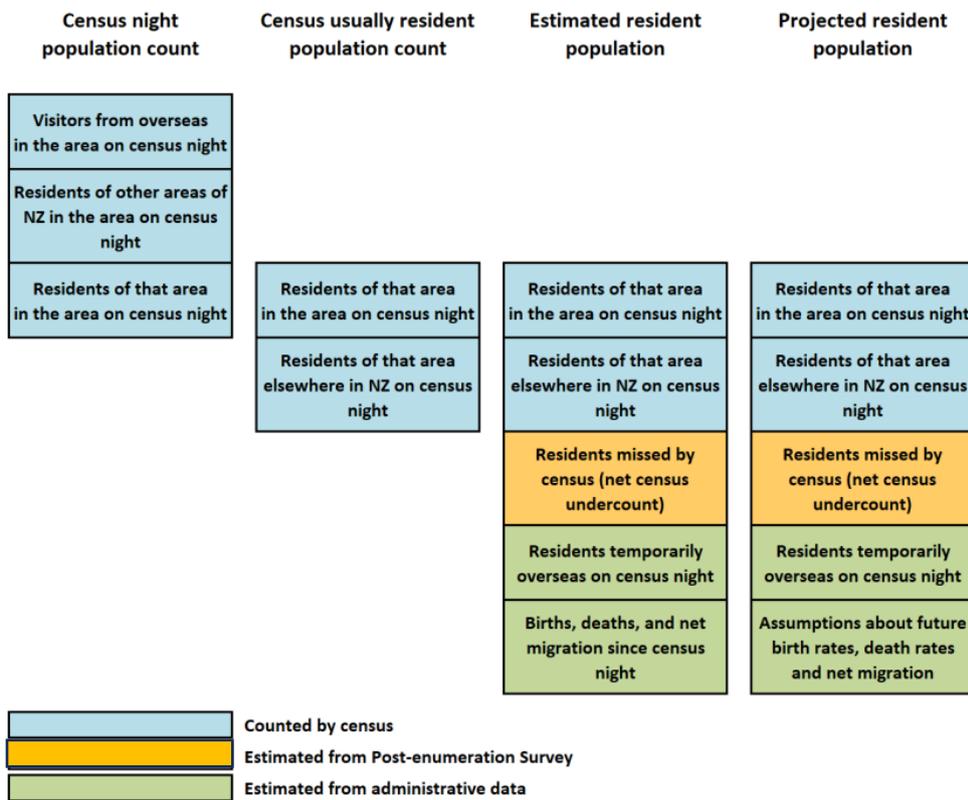
All datasets have limitations in terms of ethnicity data quality and coverage. For example, population coverage of datasets may vary for particular groups e.g. those experiencing homelessness or incarceration, which differentially impacts Māori. When selecting and using datasets it is important to understand the source and quality of ethnicity data, in order to make informed decisions on whether the dataset is fit for purpose, and if so, to allow the discussion and interpretation of any results. Within NZ, there is wide variation in the availability and quality of documentation on key administrative datasets. The lack of clear and consistent documentation is a barrier to Māori data sovereignty.

One of the challenges in measuring health and health inequities in NZ is due to variations in the quality of ethnicity data across datasets, and the issues this creates when calculating rates using different datasets (numerator denominator bias). In previous analyses, health datasets have been found to undercount Māori (to a greater degree) than other national collections such as education and MSD datasets (Reid et al., 2016). Therefore, it is critical that the health sector prioritises actions to improve the quality of ethnicity data on health datasets (McLeod & Harris, 2023).

StatsNZ Population Data

StatsNZ produces several key population statistics which give estimates of the population in the past, present and future. Three key population statistics are the NZ Census Usually Resident Population counts (URP), and the Estimated and Projected Resident Populations (ERP and PRP) (Figure 6). These are often used in health, both in NZ and internationally, to provide information on the size and composition of the population, including by ethnicity, and are commonly used as denominator data for population-based rates. Given the changing boundaries associated with the Health Reforms (e.g., Iwi Māori Partnership Boards and localities), additional work needs to be prioritised by StatsNZ, and strongly advocated for by central health agencies (Te Aka Whai Ora, Te Whatu Ora and Manatū Hauora) to make population statistics available for these new areas, including by ethnicity (and by other demographic factors by ethnicity, e.g., Māori females aged 40-45 years).

Figure 6 StatsNZ Population Statistics

Census night population count	Census usually resident population count	Estimated resident population	Projected resident population
Visitors from overseas in the area on census night			
Residents of other areas of NZ in the area on census night			
Residents of that area in the area on census night	Residents of that area in the area on census night	Residents of that area in the area on census night	Residents of that area in the area on census night
	Residents of that area elsewhere in NZ on census night	Residents of that area elsewhere in NZ on census night	Residents of that area elsewhere in NZ on census night
		Residents missed by census (net census undercount)	Residents missed by census (net census undercount)
		Residents temporarily overseas on census night	Residents temporarily overseas on census night
		Births, deaths, and net migration since census night	Assumptions about future birth rates, death rates and net migration

Counted by census
Estimated from Post-enumeration Survey
Estimated from administrative data

Source: StatsNZ, 2021

Census usually Resident Population

"This is a count of all people who usually live in New Zealand, or in an area of New Zealand, and are present in New Zealand on a given census night." (StatsNZ, 2021). It does not include NZ citizens who are temporarily overseas or temporary visitors to NZ. Because of lower than expected participation in the 2018 Census, administrative data were used to identify people who should have been counted (11%) and 2013 Census and other administrative data used to fill in details about them, including ethnicity (StatsNZ, 2019). The census is the sampling frame for nationally representative surveys, such as Te Kupenga (Kukutai & Cormack, 2018).

Ethnicity is sourced, in order of priority, from: self-identified ethnicity from the 2018 Census (84.4%); admin enumerated from the 2013 Census (8.2%); admin enumerated from other administrative data sources (6.2%) e.g., birth registrations and health (StatsNZ, 2019).

Estimated Resident Population

The ERP is considered the **official data for population estimates** and gives the best available measure of the size and age-sex structure of the population usually living in an area (StatsNZ, 2021). The Estimates are based on the latest census data updated for births, deaths, and migration since the census (StatsNZ, 2023). When available, the ERP is the preferred population denominator.

"The Māori ethnic group ERP at 30 June of each census year is based on the respective census counts, with adjustments for census non-response (people who did not complete census forms), net census undercount (people who were missed in the census), residents temporarily overseas on census night (RTO), and estimated population change between census date and mid-year." (StatsNZ, 2020b).

Strengths with respect to Māori health (as a count or denominator):

- Best estimate of the total Māori population (not limited to those using health services)
- Ethnicity Data collected in the Census (as the basis for the ERP) follows the NZ ethnicity standard, and as a result gives us the relatively best quality ethnicity data. E.g., as demonstrated by the higher proportion with multiple responses (compared to HSU) and higher coverage for Māori.
- Methods are well documented and accessible, including Census coverage adjustments
- Consistent time-series back to 1996 (including for Māori ethnicity).
- Standard ERP outputs are accessible online, and other data available by request.

Limitations

- Ethnicity data are not updated as frequently as total population estimates which leads to incomplete capture of ethnic mobility and migration.
- Estimates are subject to revision.
- Unclear if these data will be available for the Iwi Māori Partnership Boards (IMPB) and locality regions.

Projected Resident Population

Population estimates can be used to calculate population projections ('projected resident population') to provide information on the future population. These use assumptions about births, deaths and migration over time. These assumptions cause greater uncertainty for projected population estimates for ethnic groups (than for the total population).

In health, population projections are important for planning health services, and can be used as the denominator in population rates. PRPs are often available for use in advance as compared to many other datasets that have a time lag on their availability e.g., Census, ERP and HSU. For example, in their review of the HSU, StatsNZ used PRP to allow comparisons with HSU for Māori, by age and DHB (StatsNZ, 2022a). Similar to the ERP, the PRP has been well documented, with methods consistent over time and place.

Other Population Data

Health Service User (HSU)

The health service user dataset is relatively new, with little publicly available documentation on its development, methodology or limitations. A recent review into the HSU was undertaken by StatsNZ in the context of using this dataset for monitoring coverage of COVID-19 vaccinations delivered in

NZ. However, there is no publicly available documentation that specifically considers the relevance of the HSU dataset in measuring and monitoring Māori health and inequities, including over time.

The HSU is a subset of the NHI, and draws demographic data such as ethnicity, age, and gender from the NHI. The HSU is an estimate of the population using the health system in NZ in a given time period (previous 12 months). It is not an estimate of the NZ population. A person is included in the HSU, for a given reference period, if they:

- Use health services as evidenced by events recorded in a range of national health datasets[1] (including births and deaths) in the reference period, or

- Are enrolled in a PHO during the reference period, or

- Have received a COVID-19 vaccination regardless of residency (StatsNZ, 2022a).

Figure 7 Target populations of ERP and HSU for people in NZ at a point in time
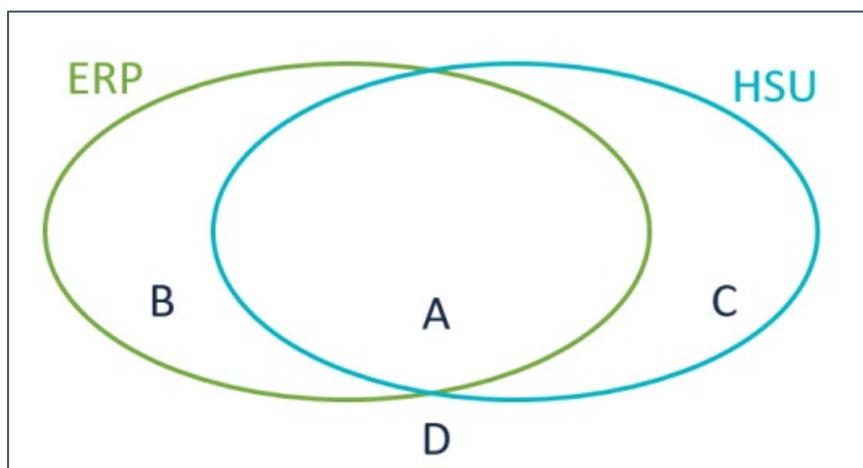
Source: Stats NZ, 2022a

There is overlap between the HSU and ERP populations, represented in Figure 7. The four-groups included in this diagram are:

A. People in the ERP and HSU (typically people resident in New Zealand who are using health services)

B. People in the ERP but not in the HSU. These are typically people resident in New Zealand who are not using health services. Māori will be disproportionately represented in this

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[1] Te Whatu Ora Datasets include: National Enrolment Service (NES), NHI, NMDS (Hospital discharge information, National Non-Admitted Patient Collection, Publicly funded community labs, Publicly funded Pharmaceutical dispensing, PRIMHD (Mental Health service use), National Mortality Collection, National Maternity Collection, General Medical Subsidy, NIR (immunisations), CIR (COVID-19 immunisation register). (Source: https://www.health.govt.nz/covid-19-novel-coronavirus/covid-19-data-and-statistics/covid-19-vaccine-data#download)

group. This group will also include some people accessing private healthcare which is only partly captured by the HSU and may be differential by ethnicity.

C. People in the HSU but not in the ERP. These are typically people <u>not resident</u> in New Zealand who are using, or have used, health services, including having COVID-19 vaccinations. This may include visitors to New Zealand, and residents of New Zealand who have subsequently emigrated e.g., people enrolled with a PHO who have moved overseas will only be removed only after their PHO enrolments lapses.

D. People not in the ERP or HSU. These are typically people not resident in New Zealand and not using health services because their visit to New Zealand is brief.

For Māori two key concerns about the HSU population are those in groups B and C. The HSU population does not include Māori who are resident in NZ but have not engaged with health services (Group B). Also, the HSU includes people who are not NZ residents (Group C). There are a number of major limitations with the HSU for Māori health analyses. These include:

- The HSU is **not Te Tiriti compliant** for analysing Māori health and equity. The HSU does not measure the total NZ population. It only includes health service users rather than the Māori population; excluding Māori who have not had access to services (Figure 7, group B). It also includes overseas visitors who used health services and may not be residents (Figure 7, group C). While the HSU only allows measures of health and equity for those with access to health care (StatsNZ, 2022a) it may concerningly be interpreted as a population rate. StatsNZ notes that the HSU is a:

  o *"conceptually complex population to define as potentially includes short term visitors to NZ and people resident overseas, while excluding people resident in NZ who do not engage with health services."* (StatsNZ, 2022a)

- As noted, there is **limited publicly available documentation** on the HSU and no evidence of Māori input into the conceptualisation and development of the HSU (a breach of Māori data sovereignty protocols or Mana Motuhake, see page 4) In particular, there is a lack of information on the data quality and limitations within HSU, especially with regards to Māori and ethnicity. Even in the limited contexts where it may be useful, it is difficult to have a clear understanding of the validity of estimates. A Te Tiriti compliant approach would enable independent Māori researchers, organisations and communities to have access to this information in order to make informed decisions about the usefulness of this dataset. Given the rapid changes in the composition of the HSU, this documentation would need to be regularly updated to reflect the current version of HSU.

- Despite the general lack of information, there are some indications of **data quality issues within the HSU**, some of which were outlined in the StatsNZ review, but others that relate to its use in measuring and monitoring Māori health and equity. Importantly, Māori are differentially underrepresented in the HSU (compared to a population dataset such as ERP). Two key reasons for this are: 1) the misclassification (undercounting) of Māori who have

accessed health services reflecting significant and longstanding undercounting of Māori on the NHI (Harris et al., 2022) and 2) the HSU excludes those people who have not accessed health services (who are likely to be differentially Māori). It is difficult to separate the impact of these two factors, the contributions of which will vary over time and by age and gender. Therefore, it is challenging to assess the accuracy of coverage of Māori in the HSU population and how well (or not) HSU represents the total Māori population in NZ (at one point in time, and over time). This is inconsistent with Māori rights to be counted (and valued) and have a powerful voice. In addition to differential undercounting of Māori generally, there is also differential undercounting of Māori by age and gender, particularly for Māori men (Harris et al., 2022). The StatsNZ review of the HSU found a significant overcount of the Pacific population compared to the PRP that was unexplained.

- The StatsNZ review raised important **concerns about use of the HSU over time** (StatsNZ 2022a). They note that, "Coverage will vary over time, with a peak in 2021/22 because of COVID-19 vaccination rollouts, so time series is inconsistent".

    o HSU is updated annually, and therefore one of the potential benefits of this dataset is that it is theoretically able to capture changes to ethnicity, gender and geography of individuals more recently than in 5 yearly censuses. However, this is dependent on the frequency of engagement with health care and frequency of data collection within health services. The ability to have more up to data is one of the arguments for using HSU as a means of identifying individuals for health services (although we note that this is not currently recommended as a use of HSU given ethical and privacy issues). Given that the HSU only includes individuals that have accessed health services, relying solely on HSU will miss any Māori who have not accessed health services in the last 12 months (the current lookback period of HSU). In addition, HSU relies upon NHI ethnicity, which is known to significantly undercount Māori, with up to 25% of Māori misclassified as non-Māori. This limits the reach of NHI (and as a result HSU) for use in accurately identifying Māori individuals for ethnically targeted services, such as the bowel screening program age 50-59, and CVD risk assessment.

    o The regular updating and changing size and composition means HSU in its current form cannot be used for time-series analyses. As seen over the COVID-19 pandemic the HSU can be strongly influenced by changes in health service use and immigration policies e.g., COVID-19 vaccination drives, border closures. Primary care enrolments data are a large contributor to the HSU. Primary care workforce shortages reduce access to primary care, which may in turn impact on the level of population coverage that the HSU dataset can achieve.

    o The HSU dataset has a 6-month lag for availability, and therefore has limitations of use for real-time monitoring. It is important to use the same HSU (i.e., for the same time period) for the numerator and denominator. This was seen in the COVID-19 vaccination rates where initial coverage rates were overestimated (Asian coverage exceeding 100%) because increases in the numerator (people being vaccinated)

were not being included in the denominator (total HSU population was an earlier point in time) (StatsNZ, 2022a).

   o An additional issue arises with respect to monitoring over time, whereby, HSU-based health rates and inequities are not comparable to previous rates measured with population-based denominators. This is problematic for monitoring progress with the elimination of inequities for Māori. Given the issues with the changing HSU dataset, and the lack of comparability with previous measures, any time series analyses require a more stable total population-based denominator such as ERP.

- One of the arguments currently put forward for justifying the use of HSU is the avoidance of **numerator/denominator bias** with regards to ethnicity because both the numerator and denominator are based on NHI ethnicity (as compared to rates using NHI ethnicity as the numerator and another source for the denominator e.g., ERP). While this is true, this benefit needs to be considered alongside some of the significant limitations of the HSU dataset with respect to measuring Māori health and inequities (including other important forms of bias such as selection bias and misclassification bias discussed above).

   o Using a HSU denominator will not generate population-based rates, as it only reflects those that access health services. For HSU rates to represent those in the total Māori population it would have to be true that the risk/rate of measured outcomes (health, coverage etc) need to be the same for those in the HSU as outside of it. There is no evidence to support this critical assumption. Māori have known inequities in barriers to care and higher self-reported unmet need for healthcare (Ministry of Health, 2022). Therefore, we would not assume that Māori who are not in the HSU are all well or have the same levels of health need as those captured in the HSU. This means that measures of inequity using HSU-based rates may differ from those calculated for the total population, and so if using HSU, population rates should also be calculated and presented in parallel.

   o Within the HSU population, ethnicity data are consistent in the numerator and denominator. HSU ethnicity is based on the NHI where there is known differential misclassification of ethnicity, particularly the undercounting of Māori, and in some cases, overcounting of non-Māori (Harris et al., 2022). The rates calculated by HSU will be affected by ethnicity data misclassification if the risk/rate of measured outcomes (health, coverage etc) differs for Māori who are correctly vs incorrectly classified as Māori. There will be little impact on the rates for non-Māori given the size of the non-Māori population. Measures of inequity may also be affected.

- One potential use for the HSU alongside other datasets to measure inequities would be to assess the quality of healthcare for Māori compared to non-Māori or sole European, by following diagnosed individuals (using NHI) through healthcare. This has previously been done using NHI. An example of this type of closed cohort approach for the examination of inequities comes from the Unequal Treatment programme (e.g., McLeod et al., 2010).

- The HSU dataset may also be useful as one source of contact information for individuals. The privacy implications of this would need to be explored. Given the underrepresentation and undercounting of Māori in HSU, it cannot be used as the sole source of contact information as it will not include Māori that have not accessed health services. In addition, there are limitations of the HSU as a source of contact information for Māori targeted services (where you only want to invite Māori), as a large proportion of Māori will be missed (due to the undercounting on NHI ethnicity data that feeds into the HSU).

IDI Estimated Resident Population

The Integrated data infrastructure (IDI) can be used to create an IDI-ERP which is a subset of "currently resident" individuals linked to the IDI spine. It includes individuals known to be alive and based in NZ (using deaths and migration data), with activity in the preceding year within any of health, ACC, taxation, and education datasets; and for those under the age of 5 years, a birth registration or visa approval (excluding visitor and transit visas) and when the record is linked in the IDI spine. The IDI-ERP has been measured to be 2% larger than the official population estimate, with variations by age and ethnicity.

Access to data within the IDI is limited to those with access to a StatsNZ accredited Data Lab and statistical and analytical expertise which is a concern in relation to Māori Data Sovereignty principles if there are structural inequities in access to data between Māori and Crown data users and policy makers. In addition, while some documentation is available on the IDI and the IDI-ERP, much of this is methodological and describes the development of the dataset rather than the methods, and limitations of the current dataset.

Ethnicity data used in the IDI ERP is source-ranked (Appendix 1), capturing ethnicity data from a range of data sources in a particular predetermined order (First ranked group in order: Census, Department of Internal Affairs (Births), Ministry of Health, Ministry of Education, ACC, Ministry of Social Development). A report by Reid et al. (2016) examines the quality of alternative rankings of the sources in Group 1 (but not groups 2 or 3 as listed in Appendix 1) and measures these against ethnicity data from the Census, at both the aggregate and individual levels. Of interest, the ranking of the Group 1 sources of ethnicity data that was found to perform the best overall, and for Māori is not the ranking currently used by the IDI (with a reversal of the order of Ministry of Education and Health data).

There are a number of concerns about the IDI and how it aligns with the principles of Māori Data Sovereignty. In particular, the lack of consent for collected data to be included in the IDI, barriers to access for Māori, the risk to personal privacy of individually linked data, and the risk of harm from inappropriate framing of research questions alongside the analysis of sensitive data (Greaves et al., 2023; Te Mana Raraunga, 2018).

Experimental Administrative Population Census (APC)

The Experimental Administrative Population Census arose out of the Census Transformation Strategy which among other things aimed to explore the feasibility of a census based on linked administrative

data in the Integrated Data Infrastructure (IDI) (StatsNZ, 2022b). **The APC data are not official statistics.** They are still being developed and tested and should not be used for routine monitoring of Māori health and equity by Government agencies. Some concerns about the performance of these data for Māori include linkage bias in the IDI, and the algorithm for ethnicity data, which seem to contradict StatsNZ ethnicity standards. For example, the APC ethnicity derivation uses birth registration as the first source of data, and prioritises the parents' ethnicities over the child's, treating ethnicity as constant over time. It is therefore unclear how accurate these ethnicity data are at an individual level. Only 0.5% of records draw ethnicity data from the Census (the highest quality source). (StatsNZ, 2022b) This dataset may become important over time and so Māori should be involved in the development to ensure that it is fit for purpose and aligns with data sovereignty principles.

Summary

Māori health and equity should be prioritised in health monitoring. This will require engagement with Māori and ensuring that Māori data needs are met. Interpretation of data should occur with an understanding of Māori health and equity in the context of broad drivers of health and equity including colonisation and racism.

This report outlines a principles-based approach to measuring and monitoring Māori health and equity. While the report focuses on analysis of national datasets, the approaches may also be relevant at the regional and local levels, for Iwi and Hapū, and can be used alongside other methods to examine health and equity for specific groups of Māori e.g. children, tangata whaikaha. High quality ethnicity data are a fundamental priority for Māori health, and currently a key limitation that must be addressed with urgency.

Any data analyses should be accompanied by a clear articulation of the positioning of the author (or organisation); have a clear purpose and rationale, draw on relevant data sources, and use methods that align with the questions to be answered. Any interpretation of data needs to also identify the strengths and limitations of the datasets and methods used (including the impact of ethnicity data quality).

Finally, this report describes key methods and underlying concepts for consideration in understanding and monitoring Māori health and inequities. These outline largely descriptive epidemiological methods at the national level, although the general concepts can be applied for particular populations of interest including regional analyses. It should be noted that the methods described here are not exhaustive, although they are a minimum for Crown health agencies to consider in their roles and responsibilities to monitor and act to address Māori health needs and equity. Other study designs, more complex analyses and methods from other disciplines are not discussed e.g. regression analyses, geographic methods, and modelling to name a few.

The key points from this report are:

1. Improving ethnicity data quality remains a fundamental priority.
2. The purpose and underlying questions should guide the choice of data and methods.
3. Data users need to critically engage with the data.
4. Māori health and equity should be prioritised in health monitoring. This will require engagement with Māori and ensuring that Māori data needs are met.
5. Methods and data sources should be clearly documented.
6. Interpretation of data needs to acknowledge the source population, the general strengths and limitations of various datasets and methods used, and the impacts on any estimates calculated.
7. Interpretation of data should occur with an understanding of Māori health and equity in the context of broad drivers of health and equity including colonisation and racism.

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Appendix 1: Source ranked codes for IDI Estimated Resident Population

The ranked sources are as follows:

Source Code	Source Name	Group Nbr	Rank Nbr
CEN	Census	1	1
DIA	Department of Internal Affairs	1	2
MOH	Ministry of Health	1	3
MOE	Ministry of Education	1	4
ACC	Accident Compensation Corporation	1	5
MSD	Ministry of Social Development	1	6
SLA_MSD	Student Loans and allowances from MSD	2	1
HES	Household Economic Survey	2	2
SOFIE	Survey of Family Income and Expenditures	2	3
LISNZ	Longitudinal Immigrant Survey: New Zealand	2	4
HLFS	Household Labour Force Survey	2	5
ACM	Auckland City Mission	2	6
GSS	General Social Survey	2	6
PIAAC	Programme for the International Assessment of Adult Competencies	2	7
NZCVS	New Zealand Crime and Victims Survey	2	8
WFF	Working for Families	3	1
SLA_SLAM_MOE	Student Loan Account Manager from MOE	3	2
SLA_SLAM_IR	Student Loan Account Manager from Inland Revenue	3	3

Source: IDI 2023