Gender and Sex Data

Protocol

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MINISTRY OF HEALTH
MANATŪ HAUORA

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Stats NZ
Practice Managers & Administrators Association of New Zealand

The interim Gender and Sex Data Protocol is a living document, and future versions will include more extensive engagement with Rainbow communities. Future versions will be supported by resources that provide guidance specific to groups such as clinicians, receptionists, administrators, and health and disability software system vendors to support them in applying the protocol to their work.

Gender and Sex Data Protocols

Contents

1. Requirement for change

All people aspire to physical and mental health and wellbeing, regardless of their gender, sex assigned at birth, or the terms they use to describe themselves. In Aotearoa New Zealand, people have different experiences in health outcomes that are not only avoidable but unfair and unjust.

Significant health inequities exist for members of our Rainbow communities, and especially for Rainbow people who are also part of other minority population such as Māori, Pacific peoples, and disabled people. The impact of these inequities is particularly evident for transgender and non-binary people, whose access to health services and health outcomes are poorer compared to other New Zealanders[1].

Clear guidelines around the collection and use of data relating to gender, pronouns, and sex assigned at birth in a health context is an important step in ensuring positive, safe, and equitable health experiences and outcomes for transgender and non-binary people.

The Gender and Sex Data Protocols (the protocol) aim to support a more inclusive and welcoming primary care sector in Aotearoa New Zealand where transgender and non-binary patients feel they are affirmed in the gender, sex, pronouns, and name options provided to them throughout their healthcare journey. Data shows that the appropriate collection and use of gender, pronouns, sex assigned at birth, and preferred name leads to better engagement with the health and disability system, and therefore improved long-term health.[2]

This protocol contains guidance for standardisation of wording and processes around collection of data relating to gender, pronouns, and sex assigned at birth for people working in Aotearoa New Zealand's primary health care sector.

1.1 Intended audience

Initially, this protocol is to be applied to the primary health care sector. Application of the protocol throughout the whole system will take time and needs to be phased into implementation. In the short term, individuals and groups in the primary health care sector to which this protocol applies are:

- collectors and processors of gender and sex data such as receptionists, administrators, and health professionals
- health and disability sector software developers and providers (such as PMS vendors).

2. Te Tiriti o Waitangi commitment

The Crown recognises Te Tiriti o Waitangi as the founding document of Aotearoa New Zealand and is committed to fulfilling its obligations as a Treaty partner. As a Crown entity, the Ministry of Health is committed to helping the Crown meet these obligations.

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[1] Veale J, Byrne J, Tan K, Guy S, Yee A, Nopera T & Bentham R. 2019. *Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand.* Transgender Health Research Lab, University of Waikato: Hamilton NZ.

[2] Ibid.

The principles of Te Tiriti o Waitangi, as stated by the Courts and the Waitangi Tribunal, provide the framework for how the Ministry of Health will meet its obligations. The 2019 Hauora report[3] recommends the following principles for the primary health care sector:

- **Tino rangatiratanga**: The guarantee of tino rangatiratanga, which provides for Māori self-determination and mana motuhake in the design, delivery, and monitoring of health and disability services.
- **Equity:** The principle of equity, which requires the Crown to commit to achieving equitable health outcomes for Māori.
- **Active protection**: The principle of active protection, which requires the Crown to act, to the fullest extent practicable, to achieve equitable health outcomes for Māori. This includes ensuring that it, its agents, and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.
- **Options:** The principle of options, which requires the Crown to provide for and properly resource kaupapa Māori health and disability services. Furthermore, the Crown is obliged to ensure that all health and disability services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.
- **Partnership:** The principle of partnership, which requires the Crown and Māori to work in partnership in the governance, design, delivery, and monitoring of health and disability services. Māori must be co-designers, with the Crown, of the primary health system for Māori.

The implementation of the protocol will help to meet the Crown's Te Tiriti o Waitangi obligations, especially regarding tino rangatiratanga, equity, and active protection, by taking steps towards ending discrimination against takatāpui, transgender, and non-binary people through more inclusive recording of gender and sex in health settings.

While recognising the Crown's commitment to honouring Te Tiriti o Waitangi, it is also important to note that the principle of equity must also be applied more broadly to other vulnerable population groups including (but not limited to) Pacific peoples and disabled people.

Collecting high-quality gender and sex data will assist the Government to disaggregate health trends by gender and sex and effectively monitor its performance to improve health outcomes and achieve health equity, especially for takatāpui Māori.

Collecting good data will also help the primary health care sector to reach the goals of Whakamaua: Māori Health Action Plan 2020- 2025. Adoption of this protocol will also contribute to redressing the impact colonisation has had on Māori.

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[3] New Zealand. Waitangi Tribunal, author. 2019. *Hauora : report on stage one of the Health Services and Outcomes Kaupapa Inquiry / Waitangi Tribunal.* Retrieved from forms.justice.govt.nz.

3. Patient safety

When working with sex and gender data, it is imperative that no assumptions are made that the patient is 'out' to everybody and in all situations, or that they would be safe if this information was shared more broadly than what the patient has consented to.

When changing names or gender information on the National Health Index (NHI), including National Enrolment Service enrolments, the patient must be informed and given the opportunity to opt out of answering particular questions, or not to have the information they have provided used to update the NHI. If updated, this information will be visible to anyone who has access to information on the NHI across the health and disability system and government sectors.

4. Background

The colonisation of the various islands in the Pacific by European settlers in the 1800s disrupted the state of sex, sexuality, and gender diversity of te ao Māori (the Māori world) and other Pacific cultures, instead bringing Victorian and Christian attitudes to gender roles, morality, and sexuality. Colonisation brought British laws that denied the basic human rights of Rainbow people.

Under British law, sexual relations between men were criminalised with harsh punishments. Sexual relations between women have never been criminalised in Aotearoa New Zealand, but women who engaged in such relations could be sent to government institutions or committed for psychiatric treatment[4].

Homosexuality was decriminalised in New Zealand in 1986, however many people in Rainbow communities still experience discrimination and violence based on their gender identities and sexual orientation.

4.1 The difference between gender and sex assigned at birth

To date, the collection of gender and sex assigned at birth in Aotearoa New Zealand's health and disability sector has been nationally inconsistent and not fit for purpose. Gender and sex data is collected and used by health sector planners, funders, and providers to design and deliver policies, services, and programmes. Accurate data collection will enable targeted planning, funding, and services to Rainbow communities.

Historically, data collection systems have only collected one item of information. This means that sex at birth and gender have become conflated, and it is difficult to ascertain which is being recorded. In many cases, there is a need for both gender and sex assigned at birth to be recorded in the health setting, such as for health screening purposes.

In April 2021, Statistics New Zealand (Stats NZ) released the statistical standard for gender, sex, and variations of sex characteristics. The statistical standard stated that:[5]

- gender refers to someone's social and personal identity as male, female, or another gender or genders that may be non-binary

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[4] Rainbow Mental Health. 2019. *Supporting Aotearoa's rainbow people: A practical guide for mental health professionals.* Wellington: Youth Wellbeing Study and RainbowYOUTH.

[5] Stats NZ. 2021. *Statistical standard for gender, sex, and variations of sex characteristics*. Retrieved from https://www.stats.govt.nz/methods/statistical-standard-for-gender-sex-and-variations-of-sex-characteristics.

- gender may include gender identity and/or gender expression
- a person's current gender may differ from the sex recorded at their birth and may differ from what is indicated on their current legal documents
- no legal proof or documentation is needed to update gender
- a person’s gender may change over time
- some people may not identify with any gender.

Stats NZ notes that the language people use to describe their gender continues to evolve over time. Additionally, there is ongoing work to translate gender classification categories into Te Reo Māori based on concepts and not just literal translations. For example:

- Male / Tāne
- Female / Wāhine
- Another gender / He ira kē anō

Collecting accurate gender data improves the health outcomes and quality of life of transgender and non-binary people.[6] Transgender and non-binary persons whose identity is not adequately recognised experience barriers to enjoying good health.[7]

4.2 Out of scope

The protocol is not intended to provide clinical guidance or substitute for gender-affirming care guidelines. It also does not lead to contractual requirements for providers.

While patients and/or consumers will have access to this public document they are not the intended audience of the document.

Recording of intersex variations is also out of the scope of this protocol. Intersex people – those with innate variations of sex characteristics – will still be able to have their gender captured correctly using this protocol.

Further information about intersex can be found on Intersex Trust Aotearoa New Zealand’s website here: www.ianz.org.nz.

5. Gender

5.1 Collection of gender information

This section details the processes relating to the collection and confirmation of gender data from a respondent. In most cases, ‘asking’ means giving the respondent a form (paper or electronic) to complete. In some instances, it may mean reading out the question, such as over the telephone, on a video call or with a blind person.

The information will be recorded and shared, along with the patient’s pronouns, NHI, and other demographic information (such as ethnicity). The purpose is to support clinical care and assist with reporting by funded or part-funded services.

Where information will be used to update gender on the NHI, including National Enrolment Service (NES) enrolments, the patient must be informed and given the opportunity to opt

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[6] Oliphant J, Veale J, Macdonald J, Carroll R, Johnson R, Harte M, Stephenson C, Bullock J. 2018. *Guidelines for gender affirming healthcare for gender diverse and transgender children, young people and adults in Aotearoa, New Zealand*. Transgender Health Research Lab, University of Waikato: New Zealand.

[7] United Nations General Assembly. 2018. *Protection against violence and discrimination based on sexual orientation and gender identity*. Retrieved from https://undocs.org/A/73/152

out of answering these questions, or not to have the information they have provided be used to update the NHI. For example, updating gender on the NHI makes it available to providers across the health sector such as general practitioners (GPs), afterhours clinics, hospitals, family planning clinics, and many other providers across the government sector.

Respondents may be patients, their carer, guardian, or support person.

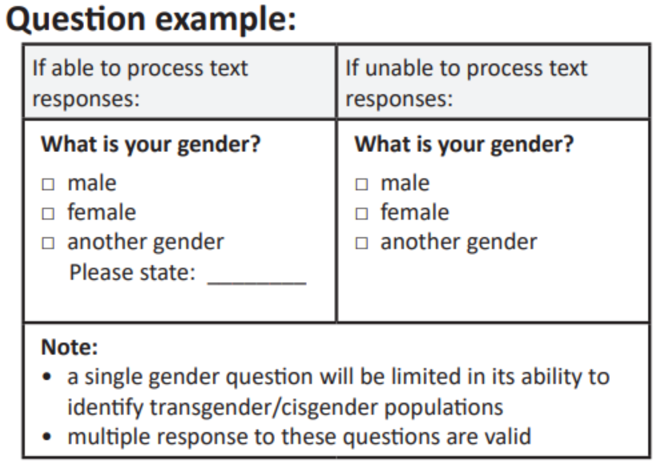
Gender is not determined based on a person’s name, title, physical appearance, or speech, and a person needs to be able to change their recorded gender without a requirement for evidence. The respondent must define their own gender regardless of collection method - for example, in-person contact, use of a paper form, electronic collection, or telephone.

The collector should not:

- guess any respondent’s gender
- complete the question on behalf of the respondent based on what they perceive to be the respondent’s gender
- change a respondent’s gender if they disagree with the answer.

Stats NZ’s best practice gender question is shown below in Figure 1.[8]

Figure 1: ‘What is your gender?’



Question example:

If able to process text responses:	If unable to process text responses:
What is your gender? ☐ male ☐ female ☐ another gender Please state: _________	**What is your gender?** ☐ male ☐ female ☐ another gender
Note: • a single gender question will be limited in its ability to identify transgender/cisgender populations • multiple response to these questions are valid	

The use of ‘another gender’ category is in line with Stats NZ’s current recommendations as a minimum third gender option for classifying responses other than male or female. ‘Another gender’ replaces the pre-existing ‘other’ and ‘gender diverse’ categories.

HISO 10046:2021 Consumer Health Identity Standard specifies the codes representing these categories for use in the NHI and other systems storing personal health information.

5.2. Output of gender information

Display/User Interface Considerations: The patient’s gender will be displayed alongside other demographic data like name and date of birth. If available, it is desirable to display the text response provided by the patient.

Access: Gender is available to all system users.

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[8] Stats NZ. 2021. *Guide to collecting gender, sex, and variations of sex characteristics data*. Retrieved from https://www.stats.govt.nz/assets/Uploads/Methods/Statistical-standard-for-gender-sex-and-variations-of-sex-characteristics/Download-data/Guide-to-collecting-gender-sex-and-variations-of-sex-characteristics-data.pdf

Referrals/letters/documents/claiming forms: The patient's gender will be used (when required) when creating correspondence such as referrals, letters, documents, and claiming forms. The text response provided by the patient should be included rather than a classification.

Electronic messaging between systems should use the agreed standard codes and display terms specified by HISO 10046:2021 Consumer Health Identity Standard and used in the HL7 FHIR Patient resource profile for New Zealand.

Reporting: The gender data should be used as the basis for reporting where gender breakdowns are required. Sex assigned at birth should only be used where it is clinically and specifically relevant and should not be visible outside of clinical areas.

6. Pronouns

6.1 Pronoun definition

Pronouns are words used to refer to people (for example, she/her, he/him, or they/them). Some people do not use any pronouns.

Pronouns are a patient's decision, and it is up to them which pronouns they want to have recorded for all their healthcare encounters. It is important to note that not all people feel safe, or are safe, using their pronouns universally.

It is important that people have the opportunity at any point, if freely chosen, to change the pronoun(s) recorded.

6.2 Collection of pronouns

Pronouns should be collected using the question: 'What are your pronouns?'

Avoid using the words 'preferred' [pronouns] or 'gender' [pronouns] when asking about pronouns.

Pronouns are not mandatory and there should be the option to leave the response blank.

6.3 Output of pronouns

Display/user interface considerations: The patient's pronouns will be displayed alongside the person's name and gender.

Access: Pronouns are available to all system users.

Referrals/letters/documents/claiming forms: The patient's pronouns should be used in all referrals/letters and other written documents. Where a person does not provide a pronoun and one is required then the pronoun that relates to the patient's gender (he/him, she/her, they/them) will be used instead.

7. Sex assigned at birth

7.1 Definitions of sex assigned at birth

The 'sex assigned at birth' is what is recorded at the time of birth.

As discussed above, a person's gender may differ from their sex assigned at birth, and from what is recorded on their birth certificate.

7.2 Collection of sex assigned at birth

Guidance on how to interact with patients when collecting information on sex assigned at birth has been developed by Stats NZ. The guidance states there may be certain health care contexts where both sex and gender information are required for distinct purposes.

Determine if you need to know the respondent's/population's sex assigned at birth for a specific reason.

This information is collected and used on a need-to-know basis, and where relevant.

Sex assigned at birth must only be collected in a clinical context by a health provider and not by administrative staff. Other health and disability workers such as youth health workers, social workers, or mental health kaiāwhina may be given this information by the respondent. If a disclosure regarding sex assigned at birth is given, the health worker should ask the person if they wish to have this information recorded.

7.3 Output of sex assigned at birth

Display/user interface considerations: The sex assigned at birth will be displayed with other clinical information. It must not be displayed alongside a person’s name and other demographic information that is used for administrative reasons.

Access: The sex assigned at birth must only be accessible to clinical staff, as with other clinical information.

Referrals/letters/documents/claiming forms: Sex assigned at birth should only be included when it is clinically necessary and should be included along with other clinical notes.

Electronic messaging between systems should use the agreed standard codes and display terms specified by HISO 10046:2021 Consumer Health Identity Standard and used in the HL7 FHIR Patient resource profile for New Zealand.

Reporting: Sex assigned at birth should not be used as the basis for reporting where gender breakdowns are required. Sex assigned at birth should only be used where it is clinically and specifically relevant. Examples include prescribing tools such as special authority forms, and audits and recalls for health screening purposes. Sex assigned at birth should not be visible to non-clinical applications or workers.

8. Names

8.1 Collection of names

It is up to an individual to determine the name that is recorded on their health records. This enables them to feel safe, respected, and have their privacy maintained.

Sometimes people will need to provide further information to determine eligibility for publicly funded services, however it is important to note that many people cannot afford or are unable to change their name legally, so their official name may differ from their stated name.

Other names the patient uses and the name that appears on their official documents like their birth certificate or passport may also be collected. Other names (such as middle names and surnames) should be collected and may support the accurate confirmation of identity and ensure the person's records can be located and may be required to access funding for the patient.

Where information will be used to update name on the NHI, including National Enrolment Service (NES) enrolments, the patient must be informed and given the opportunity to opt out of answering these questions, or not to have the information they have provided be used to update the NHI. For example, updating gender on the NHI makes it available to providers across the government sector such as GPs, afterhours clinics, hospitals, family planning clinics, and many other providers across the government sector.

8.2 Output of Names

Display/user interface considerations: The patient's preferred name should be displayed with their gender and pronouns. Other names should be accessible for the purposes of confirming identity and accessing the correct patient's records but should not be prominent.

Access: Preferred names are available to all system users. Other names should not be prominent and should only be available where there is a purpose.

Referrals/letters/documents/claiming forms: The patient's preferred name should be used in all referrals/letters and other written documents. Other names can be included for the purposes of confirming identity.

9. Assisted responses

9.1 Assisted response

Where the respondent has a disability that will hinder their ability to complete questions of gender and/or sex assigned at birth, an appropriate aid should be provided.

9.2 Proxy response

Where the respondent is unable to complete gender and/or sex assigned at birth questions themselves, it is desirable to collect gender and/or sex assigned at birth data using a proxy response. The method to follow in two different circumstances is described below.

- **Incapacity**: If the respondent is incapable of completing gender and/or sex assigned at birth questions, where possible the nominee or next of kin should answer the question/s on behalf of the respondent. If there is no one accompanying the respondent, you should:
  - locate the next of kin and ask them to provide a proxy response
  - wait until the respondent can complete gender and/or sex assigned at birth questions.
- **Children:** Where the respondent is a child, the parent/guardian(s) must always be given the opportunity to complete gender and/or sex assigned at birth questions.

There is no legal or recommended age at which a child can respond on their own behalf. When children can understand the concept of gender and sex, they should be given the opportunity to complete the question themselves. The appropriate age for such understanding is a matter of judgement.

10. Glossary of terms[9]

For a more complete glossary of terms relating to sexual orientation, gender identity and expression, and sex characteristics, please refer to page 61 of *PRISM: Human Rights issues relating to Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (SOGIESC) in Aotearoa New Zealand - A report with recommendations*.

Cisgender – A person whose gender aligns with their sex assigned at birth.

Gender diverse – An umbrella term used by some who identify outside of the male/female gender binary. Being transgender can be one way of being gender diverse, but not all gender diverse people identify as transgender and vice versa.

Gender identity – Refers to each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical, or other means) and other expressions of gender, including dress, speech, and mannerisms.

Intersex – A person whose sex characteristics are more diverse than typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns.

LGBTQIA+ – An acronym of different identities within Rainbow communities, including Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual. The plus denotes inclusion of other terms not listed.

Non-binary – An umbrella term for gender identities which are neither male nor female.

Pacific communities – Have their own culturally specific terms relating to sexual orientation and gender identities. These concepts are just as much or more about familial, genealogical, social, and cultural selfhood.

Fa'afafine – (Samoa & American Samoa), Leiti/Fakaleiti (Tonga), Fakafifine (Niue), Akava'ine (Cook Islands), Pina (Tuvalu), Māhū (Tahiti and Hawaii), Vakasalewalewa (Fiji) and Palopa (Papua New Guinea).

Queer – A reclaimed umbrella term that encompasses identities and expressions outside of heterosexual, monogamous, and normative gender expressions.

Rainbow communities – An umbrella term commonly used in Aotearoa to describe those who have a diverse sexual orientation, gender identity or expression, and sex characteristics.

Sex assigned at birth – All babies are assigned a sex at birth, usually determined by a visual observation of external genitalia. A person's gender may or may not align with their sex assigned at birth.

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[9] New Zealand Human Rights Commission. 2020. *Prism: Human rights issues relating to Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (SOGIESC) in Aotearoa New Zealand - A report with recommendations.* Wellington: New Zealand.

Sex characteristics – Refers to each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty.

Sexual orientation – Refers to each person's capacity for profound emotional, affectional, and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender, or more than one gender.

Takatāpui – A traditional Māori term which means 'intimate companion of the same sex.' It has been reclaimed by some Māori to describe their diverse sexual orientation, gender identity or expression, and sex characteristics.

Tangata ira tāne – A te reo Māori term which roughly translates as transgender man.

Transgender – An umbrella term for a person whose gender differs from their sex assigned at birth. Transgender people may be binary or non-binary, and some opt for some form of medical intervention (such as hormone therapy or surgery). Used as an adjective rather than a noun, and often shortened to 'trans.'

Transition – Steps taken by transgender people to live in their gender which may include social, legal, or medical aspects. A social transition may include changing clothes, hair, pronouns, or name; a legal transition may include changing name and/or gender marker on legal documents; and a medical transition may include medical treatments such as laser hair removal, hormone therapy, or various surgeries. There are no wrong or right ways to transition; each person will have their own personal goals.

Trans man – A man who was assigned female at birth.

Trans woman – A woman who was assigned male at birth.

Transsexual – An older term considered to be outdated by some in younger populations. Transsexual is not an umbrella term; those who prefer this term often see it as an important distinction from transgender. It may refer to a person who has had or is in the process of changing their body to affirm their gender.

Whakawahine – There is no direct English translation, but roughly translates as trans woman. More literally, it translates as being or becoming, in the manner or spirit of a woman.