Health New Zealand
Te Whatu Ora

Interim guidance – collection and transmission of gender and sex related information in the health system.

October 2024

Background

Health NZ is developing a standard on the collection and sharing of gender and sex related information that will be ratified by the HISO standards committee. This standard is person-centred, and has been developed in close collaboration with people with expertise in transgender and non-binary health. Careful consideration is needed to ensure that sex related information is only available when it is clinically relevant; gender and sex related information should be collected, shared and used with transparency and consent in a way which protects safe healthcare. This document provides interim guidance while the standard is finalised.

Transgender, Takatāpui, and non-binary people have inequitable access to health services, experience discrimination when seeking and accessing care, have worse health outcomes than the general population, and have experiences of abuse and stigmatisation when seeking health services[1,2]. Privacy, consent, and safety are critical when collecting, sharing, and using personal gender and sex related information. Concerns about inappropriate or unconsented disclosure of this information can act as a barrier for patients to access care[3].

Gender refers to a person's social and personal identity. A person's gender may differ from the sex recorded at their birth and may differ from what is indicated on their current legal documents. Sex is based on a person's sex characteristics, such as their chromosomes, hormones, and reproductive organs. Definitions of key concepts can be found at: https://www.stats.govt.nz/methods/data-standard-for-gender-sex-and-variations-of-sex-characteristics/#glossary

Accurate gender and sex related information can support the provision of appropriate healthcare. What information is required is contextual, and the sex related information which is needed for clinical purposes is complex and varied. Sex data does not always provide the relevant clinical information. For example, knowing that someone was recorded as female at birth does not tell you if they have a uterus or cervix, have had a hysterectomy, or if they are receiving hormones which may alter their laboratory reference ranges. The forthcoming standard will provide more in-depth guidance on collecting sex related information, including for clinical purposes. A person's gender is most relevant in health as a core demographic, and as an important aspect of their personal and social identity.

[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] Fenaughty, J., Ker, A., Alansari, M., Besley, T., Kerekere, E., Pasley, A., Saxton, P., Subramanian, P., Thomsen, P. & Veale, J. (2022). Identify survey: Community and advocacy report. Identify Survey Team.

[3] 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.

Interim guidance

1. Transparency, autonomy, and consent should be the foundation for collecting, sharing, and using gender and / or sex related information. This acknowledges Te Tiriti o Waitangi principle of Tino Rangatiratanga to allow self-determination and autonomy over sensitive information.
2. Only gender should be available from and supplied to the NHI.
3. Gender should be collected and transmitted as the dominant / primary patient identification administrative demographic field.
4. Sex related information can also be collected. If this is collected:
   a. Sex related information should be entered into a separate designated field.
   b. Sex related information should never be mandatory. It should only be recorded with the informed consent of the patient, including who will have access and how the information will be used.
   c. Sex related information should only be visible to people who need to know this information.
   d. Sex related information should never be visible nor displayed publicly, for example on patient IDs or banners.
   e. Sex related information should only be transmitted to systems that need the information for clinical purposes.
   f. Sex parameters for clinical use can be included in specific segments as a pre-adoption to modern sex and gender transmission rules.
5. All systems which collect patient names should have a 'Name to use' field. This field should record the name the patient uses in everyday life. In some existing systems this is called 'Preferred name', we recommend changing this to 'Name to use'.
   a. 'Name to use' should be entered into a designated field.
   b. Legal name fields can be collected, but should never be displayed publicly.
   c. Legal name fields should only be visible to people who need to verify identity, for example to check if someone is eligible for health services.
6. Systems which collect patient information should have the capability to capture pronouns. These fields should not be mandatory. Pronouns can be collected with patient consent, where the provider understands how to appropriately collect and use this information. The HISO standard will include guidance on appropriate collection and use.
7. Titles (eg Mrs, Mr, Ms, Mx etc) are not a requirement in systems which collect patient information. Where they are included, they should be optional for each patient - there should not be a requirement to have a value in the Title field. The Title field should never auto-fill based on other fields.
8. All clinical systems which accept referrals for services should remove any requirements related to gender or sex. Any individual should be able to be referred for any service or test if it is clinically relevant, regardless of their sex or gender. For example, people with a gender marker of 'M' should be able to be referred for cervical screening.

This guidance reflects the forward direction of recommended change. We are aware that some existing systems only have one field to collect gender and sex information. In these instances, gender should be collected by default in these systems.

a. For specific clinical purposes the gender value can be changed to align with a person's sex, with explicit consent from the patient.
b. If this change will override the value on the NHI, then this must be done with patient consent, including whether to change the value back once the clinical service has received the information.

For people collecting gender and sex related information:

- Think about why you're asking, and what information is most relevant for the purpose(s) for which you're collecting the information.
- Ask inclusive questions that are respectful, relevant, and enable the person to share or not share information as they prefer.
- Provide clear information about what is being recorded and why, who will have access to that information, and any limits of confidentiality.

This guidance is based on feedback from community stakeholders with lived experience, with a focus on maintaining patient autonomy, safety, and privacy. We have also received input from a variety of clinicians. This interim guidance will be reinforced and superseded by the HISO Gender and Sex Data Protocols when these are finalised.

Risks

Clinical risk. There are existing clinical risks from the systems which collect gender and sex related information in the same field. For example, when clinicians need sex-related information about a person's physiology or that they are transgender, but only have access to gender or a field which is not clearly defined. There are also risks due to misunderstanding of what is actually present in a specific field.

Privacy risks. When sex related information is collected and shared between systems as a core demographic instead of or as well as gender, this can identify that someone is transgender. This may impact transgender people accessing healthcare due to mistrust and concerns about discrimination and a lack of safety. There are also risks when only a single field is available, when how a person presents may not align with social expectations of that gender or sex.

The interim guidance above does not solve all existing clinical risks, it prioritises the autonomy and consent of the individual to make informed decisions and reinforces the need for context around all data. Forthcoming information from the HISO standard will include options for safely collecting and transmitting sex related information, which address clinical information needs. This needs careful thought, including what sex related information is relevant in a specific context. Other solutions such as hormone profiles and organ inventories can be considered for the long term.

Technical considerations

- The technical details of implementing this guidance will involve user interface changes and an "opt in" build to address consumer sex where relevant. A full change management program to align systems will need to accompany the release of the HISO standard.
- Health information systems should send gender to the NHI, as per the Consumer Health Identity Standard. Sex related information is not collected on the NHI.
- Gender should be collected and transmitted as the primary patient identification administrative demographic field in HL7. HL7 2.9.1 and FHIR have separate fields and will be harmonized with the user interface display of the data elements. Pre-adoption guidelines of these standards is available for versions below HL7 2.9.1
- To ensure seamless transmission of gender information all patient administration system (PAS) and / or electronic medical record (EMR) will consume and transmit gender as the primary patient identification segment, as they are the system responsible for sending this information to downstream systems.