Transgender Health recommendation: Patient Management System identifiers

This outline covers off a best practise recommendation for recording information about sex, gender and identifying information such as patient name in Patient Management Systems (PMS).

The underlying principles of this recommendation are:

- Patient confidentiality
- Self identified gender and name
- Transgender or gender diverse status is only disclosed or discussed when medically relevant

Sex vs Gender

Sex and gender are typically conflated in regular use, further reinforced in that for the majority (those who are non-transgender) sex and gender closely align. However they are not interchangeable.

Sex, more specifically 'sex assigned at birth' or 'natal sex', relates to the chromosomal, hormonal and reproductive organs. For the majority, this is XX/female or XY/male. A third category is Intersex (sometimes termed indeterminate on a birth certificate), which represents one of 50+ conditions that affect chromosomes, hormone balances or reproductive development.

Gender, more specifically 'gender identity', relates to an individual's experience of their own gender. This may or may not align with their sex assigned at birth. Gender can be male, female, or a wide range of other descriptors including culturally specific ones. The Stats NZ standard for Gender Identity uses 'gender diverse' as the high level third option[1].

Records

Many current PMS have a single field, labeled either 'sex' or 'gender'(but typically intended to represent both), with only two options, male or female, for each patient.

The ability to record a patients gender identity accurately in PMS is important in building trust with a transgender person. This is balanced with the need to know accurate medical information about them, for example for enrolment in screening programmes relevant to their reproductive organs.

A number of practices and clinicians have come up with work arounds to the limits of existing PMS. This typically includes making use of the notes section. However, a number of limitations are present with this approach:

- Transgender people are further invisibilised, as it is not straight forward to run reports on transgender people within a PMS database when identified in this manner.
- The use of patient notes is not consistent across clinicians. A clinician unfamiliar with the patient may not look at the notes section, or may interpret them incorrectly.

The below represents different levels to which transgender people can be identified and accurately reported in PMS.

---

[1] http://www.stats.govt.nz/methods/classifications-and-standards/classification-related-stats-standards/gender-identity.aspx

Sex, gender and preferred name

PMS should allow for separate recording of:

- Sex assigned at birth
- Gender identity
- Preferred name

Gender Identity can follow the Stats NZ standard, or be a free text field for greater allowance of self determination.

Field	Data type	Field options	Equivalent NHI field	Basis of recommendation
Sex (Sex assigned at Birth)	Coded, one character	1. Male 2. Female 3. Indeterminate / Intersex	*None**	The New Zealand Government allows for recording male or female on a birth certificate, unless sex was indeterminate at birth. https://www.govt.nz/browse/nz-passports-and-citizenship/changing-your-gender/change-the-gender-on-your-birth-certificate/
Gender (Gender Identity) *Strict, Stats NZ standard*	Coded, numerical	1. Male 11. Male/Tāne 2. Female 21. Female /Wahine 3. Gender diverse 30. Gender diverse not further defined / Ira tāngata kōwhiri kore 31. Transgender male to female / Whakawahine 32. Transgender female to male / Tangata ira tāne 39. Gender diverse not elsewhere classified / Ira tāngata kōwhiri kore	Gender*	http://www.stats.govt.nz/methods/classifications-and-standards/classification-related-stats-standards/gender-identity.aspx
Gender (Gender Identity) *Less prescriptive, free text*	Free text	Gender: _____	*None**	Greater allowance for transgender people to define their own gender within PMS increases engagement with healthcare. A free text field can be used in conjunction with the strict, coded gender field above.
Preferred name	Free text	Name: _____	Given name & Preferred name indicator	

Note: The Ministry of Health have indicated they are considering an update to the NHI that would allow for separate identification of sex and gender, including a free text option for gender.

Organ inventory, treatments and procedures register

Where an additional level of clarity is desired, a PMS can separately record the reproductive organs of a person, and/or the procedures and treatments accessed.

An example of use is a person who is female assigned at birth, and their gender is male. From that information it cannot be determined if they have accessed a double masectomy, or hormone therapy.

Recommended options from the World Professional Association of Transgender Health EMR working group[2]:

Organs for inventory	Treatments and procedures register
▸ Penis	▸ Hormone therapy, current user
▸ Testes	▸ Hormone therapy, past user
▸ Prostate	▸ Vaginoplasty, penile inversion
▸ Breasts	▸ Vaginoplasty, colon graft
▸ Vagina	▸ Phalloplasty, abdominal flap
▸ Cervix	▸ Phalloplasty, free flap
▸ Uterus	▸ Metoidioplasty
▸ Ovaries	▸ Scrotoplasty
	▸ Urethroplasty
	▸ Scalp advancement
	▸ Forehead reconstruction
	▸ Reduction thyrochondroplasty
	▸ Laryngeal feminization surgery
	▸ Soft tissue filler injections
	▸ Bilateral total reduction mammoplasty
	▸ Voice surgery
	▸ Other unlisted surgical procedure

Additional information, such as the date of a procedure, initiation/termination of hormone treatment, may also be recorded.

Patient confidentiality

There are a number of clinical settings where a persons sex assigned at birth and legal name may not be relevant:

- At clinic reception
- When being treated for a non-gender related aliment, such as a broken arm

Therefore, by default it is recomended the PMS display limited information about the patient. For example:

- Preferred name only is displayed
- Self defined gender identity is displayed
- Sex assigned at birth is not displayed

Where some information has not been provided, the PMS could fall back to using other fields:

Information to display:	Name	Gender
Field to use:	*In first case:* Preferred name *If not available/complete, use:* Legal name	*In first case:* Gender (free text) *If not available/complete, use:* Gender (strict)

2 https://www.ncbi.nlm.nih.gov/pubmed/23631835

		If not available/complete, use: Sex

Appendix 1: Example of procedure to work with existing PMS for preferred name

Change of name procedure at Sexual Health (ARSHS) for new transgender clients

1. Referral is received at ARSHS for transgender client.

2. CSR staff phone the patient to book them for an appointment.

3. CSR staff asks the patient what name (first name) they want to have entered into the hospital system.

4. CSR staff change the patient's first name in CMS and HCC.

5. When the prompt to add the previous name to the Alternative names tab comes up, click YES – this will ensure the previous name details are recorded in CMS.

6. CSR staff then email the Data Quality Clerks with the following information:
   - NHI
   - Original details BEFORE the change in CMS
   - What the details were changed to
   - Confirmation that the patient was verbally asked for the change, by whom, and the date

7. When patient arrives at ARSHS they fill out the:
   - ADHB Registration Form to note the change in name and/or gender
   - Clinical Alert Notification form (if gender changed)
   - Sexual Health change of name/gender form

This is required so that when the MOH contact the data quality team asking for verification of significant changes to NHI demographic details, they will be able to quickly check and send confirmation that the change is legitimate.