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| Guidance note: Inclusive collection and reporting of sex and gender data  |
|  |
| October 2023 |
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# About this guidance

This guidance note supports staff in Victorian health services to understand, plan and implement changes to sex and gender data reporting requirements. In particular it provides guidance on how to collect patients’ sex and gender information respectfully and sensitively in line with the new requirements.

# What is changing?

The Department of Health has approved changes to **two** data elements within its hospital (public and private and day procedure centres) data collections:

* Victorian hospitals are to report data on patients’ ‘**sex at birth**’ rather than ‘sex’ (effective 1 July 2024)
* Victorian hospitals are to report on patients’ ‘**gender**’ (optional from 1 July 2023, mandatory from 1 July 2024)

These changes apply to ESIS (Elective Surgery Information System), VAED (Victorian Admitted Episodes Dataset), VEMD (Victorian Emergency Minimum Dataset) and VINAH (Victorian Integrated Non-Admitted Health Minimum Dataset). Find out more about the [annual changes to Victorian health service data reporting requirements](http://www.health.vic.gov.au/data-reporting/annual-changes) <www.health.vic.gov.au/data-reporting/annual-changes>.

# Why is it important to collect and report data on sex and gender?

#### Current data collections don’t reflect Victoria’s diversity

Before these changes, hospitals have only been required to collect and report a patient’s sex. Some people have a different sex or gender to what was assigned to them at birth or a gender that sits outside of the spectrum of male and female. It is important that trans and gender diverse people are able to accurately inform health services of their sex and gender in a safe and inclusive way.

#### Collecting a patient’s sex at birth and gender enables better healthcare

Trans and gender diverse people may have distinct healthcare and other support needs. Health services that have information about both a patient’s assigned sex at birth and their gender will generally be in a better position to provide clinically appropriate and inclusive healthcare to trans and gender diverse people.

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| “Improving LGBTIQ+ data collection to build evidence will enable us to get a better picture of how LGBTIQ+ Victorians experience all parts of their lives. By building this picture, we can better identify needs, understand how services are performing and know where we need more investment to support LGBTIQ+ people.”Pride in our future: Victoria’s LGBTIQ+ Strategy 2022-32  |

#### Accurate health data enables government planning for more equitable health outcomes for LGBTIQA+ Victorians

Data on patients’ sex at birth and gender will be used to design policies, programs and services that achieve more equitable health outcomes for LGBTIQA+ Victorians. It will also help the Victorian Government deliver on *Pride in our Future: Victoria’s LGBTIQ+ Strategy 2022-32* under Priority Area 3: Visibility to inform decision making.

# What is the difference between sex and gender?

The Victorian Government has adopted and promotes inclusive definitions of gender, in line with the *Sex Discrimination Act 1984, Safe and Strong: A Victorian Gender Equality Strategy,* and *Pride in Our Future: Victoria’s LGBTIQ+ Strategy 2022-32*.

## Gender

* Gender is part of a person’s personal and social identity. It refers to a way a person feels and sees themselves. A person may choose to present their gender to others through their name, outward appearance, speech, mannerisms and dress.
* Many people understand their gender as female or male. Some people understand their gender as a combination of these or neither.
* Many people are cisgendered, while a smaller number of people identify as a different gender from the sex they were assigned or presumed at birth.
* Gender can be fluid, meaning a person's gender may change over the course of their lifetime.

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| **GENDER: What definitions are commonly used?** A **trans** (short for **transgender**) person is someone whose gender does not exclusively align with the one they were assigned at birth. **Gender diverse** refers to a range of genders expressed in different ways. There are many terms used by gender diverse people to describe themselves. A **non-binary person** is someone whose gender sits outside of the spectrum of male and female. A person might identify solely as non-binary or relate to non-binary as an umbrella term and consider themselves genderfluid, genderqueer, trans masculine, trans feminine, agender, bigender or something else.**Sistergirl** and **brotherboy** are terms used in some Aboriginal and Torres Strait Islander communities to describe trans and gender diverse people as a way of validating and strengthening their gender identities and relationships, with an understanding and reference to someone’s inner spirit as female or male. Sistergirls and brotherboys may be non-binary, female or male. While most often used among gender diverse people, the use of these terms varies between locations, countries and nations, and may not specifically define gender identity. For example, in some communities these terms are used without any reference to gender diversity including among some lesbian and heterosexual Aboriginal and Torres Strait Islander women who may refer to themselves as ‘sistagirls’, ‘sistas’ or ‘tiddas’, and some gay Aboriginal men may also refer to themselves as ‘sistas’. **Gender incongruence** is the preferred sexual health classification of transgender and gender diverse people by the World Health Organisation (WHO). It replaces the stigmatising term ‘gender dysphoria’ which was used previously. **Cis (short for cisgender**) describes individuals whose gender is the same as their sex assigned at birth.For more info see the [LGBTIQ+ Inclusive Language Guide](http://www.vic.gov.au/inclusive-language-guide) <www.vic.gov.au/inclusive-language-guide> *A note on terms: While we have provided definitions for some common terminology, this list is not exhaustive, and some people may prefer to use other terms.*  |

## Sex

* A person’s sex is usually determined at birth or prenatally, based on the appearance of their sex characteristics, such as genitalia, hormones, and chromosomes.
* Sex is usually determined as male or female.
* A small number of people are born with variations in sex characteristics that differ from medical norms for female or male bodies. See more information below.
* A person's sex can change over the course of their lifetime and may differ from their sex assigned at birth.
* Legal sex is the sex on any or all identity documents. Victorian law allows some people born in Victoria to change the record of sex shown on their [birth certificate](https://www.bdm.vic.gov.au/changes-and-corrections/change-your-recorded-sex) <https://www.bdm.vic.gov.au/changes-and-corrections/change-your-recorded-sex>. People do not need to have surgery to make this change. This means a person’s current sex or legal sex may be different from their sex assigned at birth.
* Sometimes a person’s current sex is not reflected in their identity documents and is therefore different from their recorded ‘legal sex’.

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| ***Variations of sex characteristics - Intersex***Some people are born with a variation to physical or biological sex characteristics including chromosomes, hormones or anatomy. There are many different intersex variations that can be identified prenatally, at birth, puberty, or adulthood. People with intersex variations will use a range of different terminology to name their bodies and experiences. Some use the term ‘intersex’, which is also signified by the ‘I’ in LGBTIQA+ communities. Others do not connect to the term ‘intersex’. The sex data element cannot be reliably used to identify a person as having an intersex variation because people with variations of sex characteristics are usually assigned male or female at birth or infancy, just like everyone else. Mislabelling intersex as a sex category ignores the diversity of people with innate variations of sex characteristics. Intersex people can also have any gender identity. Intersex should not be included as a gender data element. To mislabel intersex as a gender identity ignores the diversity of people with innate variations of sex characteristics.Collect sex at birth and gender data for people with variations as you would for any other patient using the guidance below. These changes to reporting requirements are not intended to account for people with variations in sex characteristics. The department is currently considering a range of reforms to improve health and wellbeing outcomes for people with variations in sex characteristics outlined [(i) am Equal](https://www.health.vic.gov.au/publications/i-am-equal) https://www.health.vic.gov.au/publications/i-am-equal>. This could result in new guidance on collecting data on variations in sex characteristics. You can read more about [recording the diversity and health needs of the intersex population](https://ihra.org.au/forms/) at Intersex Human Rights Australia website <https://ihra.org.au/forms/>.  |

# Collecting and reporting sex and gender information

While health services will only be required to report ‘sex at birth’ and ‘gender’, for inclusion and clinical care it will generally be best practice to also collect a person’s name in use, name on Medicare card, pronouns and legal or current sex.

## Name

It is important to collect a person’s ‘name in use’ or ‘preferred name’ in addition to their ‘name on Medicare card’ because some people have different legal names than the name they use, or different names on different documents. This can be due to the complexity or cost of changing a legal name or the name on official documents. Using the phrase ‘name on Medicare card’ is generally preferred by trans and gender diverse people because it explains why it is necessary for your service to know this information.

*Recommended question: What is your name in use? [write-in field / free text field]*

*Recommended question: If different, what is the name on your Medicare card? [write-in field / free text field]*

## Pronouns

Collecting a person’s pronouns is recommended because it assists your service to use the correct pronouns and shows a person that your service is committed to being inclusive of trans and gender diverse people.

*Recommended question: What are your pronouns (select all that apply):*

* *She/her [tick box]*
* *He/him [tick box]*
* *They/them [tick box]*
* *I use a different term (please specify): [write-in field / free text field]*
* *By name [tick box]*

**See page 7-10 for advice on how to use this information in a safe and affirming way.**

## Collecting and reporting on gender

Data collection systems should collect gender data in accordance with the Australian Bureau of Statistics Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables (2020).

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| Collecting data on gender | Reporting data on gender  |
| It is preferable to collect gender before collecting legal or current sex and sex at birth. The following question and terms are recommended for most health service settings. Some services, such as trans and gender diverse health services, may want to include additional options. *Question: How do you describe your gender?** *Man, boy or male*
* *Woman, girl or female*
* *Non-binary*
* *I use a different term (please specify): ………*
* *I prefer not to say*
 | A patient’s gender should be reported against the descriptors* 1. **Man, or boy, or male** (A person who describes their [gender](https://meteor.aihw.gov.au/content/750032) as man, or boy, or male)
	2. **Woman, or girl, or female** (A person who describes their gender as woman, or girl, or female)
	3. **Non-binary** (A person who describes their gender as non-binary.Non-binary is an umbrella term describing gender identities that are not exclusively male or female)
	4. **Different term** (A person who describes their gender as a term other than man/boy/male, woman/girl/female or non-binary)
	5. **Prefer not to answer** (A person who prefers not to respond on how they describe their gender)
1. **Not stated or inadequately described** (Includes: Question unable to be asked such as when the patient is unconscious or too unwell.)
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**See pages 8-10 for advice on how to use this information in a safer and more affirming way.**

#### Can a patient’s gender be updated?

The reporting of patient gender occurs during an episode of clinical care. This means that once a gender is assigned to a patient for an episode of clinical care, it remains that way for reporting purposes. However, as a person’s gender identity can change, health services should ensure that the patient gender field in record systems can be updated for future episodes of clinical care.

## Collecting and reporting on sex

#### Data collection systems should collect sex data in accordance with the Australian Bureau of Statistics Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables (2020).

Health services should collect both legal or current sex and sex assigned at birth so that the healthcare provided responds both to a person’s identity and their physical body and genetic composition.

Collection of sex at birth can be particularly sensitive for some trans and gender diverse people, including because they may have gone through a long and difficult process to change their sex. Some trans and gender diverse people may not want to disclose this information for various reasons, including not wanting to be ‘out’ to your service. It is critical that ‘sex at birth’ information is collected in a respectful and appropriate way – **see pages 8-10 for more information on how to create a safer and more affirming space for data collection**.

Incorrect sex at birth information on a patient’s health record can have substantial implications for clinical care delivery, and result in incorrect screening or treatment.

The requirement to report on sex at birth will come into effect from July 2024.

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| Collecting data on sex  | Reporting data on sex (sex at birth) |
| *Question: What was your sex assigned at birth?** *Male*
* *Female*
* *Another term (please specify): …...*

*Is this different from your current or legal sex?* *If so, what is your current or legal sex?* * *Male*
* *Female*
* *Another term (please specify): …...*
 | For reporting requirements, ‘sex at birth’ is defined as the *sex of the person as recorded at birth or infancy*.From July 2024 ‘sex at birth’ will be reported against the descriptors: **1 Male (**Persons whose sex at birth or infancy was recorded as male)**2 Female (**Persons whose sex at birth or infancy was recorded as female) **5 Another term (**Persons whose sex at birth or infancy was recorded as another term [not male or female]). |

#### What if a patient does not want to disclose their sex assigned at birth?

Collect the information your patient is comfortable to provide, to inform best possible clinical care. Also capture any concerns or preferences your patient has about disclosure of sex and gender data. For reporting purposes, link back to the descriptor ‘Another term’.

#### Can a patient’s current or legal sex be updated?

In Victoria, a person can legally change their sex without undergoing sex affirmation surgery. Consider having a procedure for patients to privately establish and change information about their current or legal sex at your service.

### **Can a patient’s sex at birth be updated?**

Sex at birth is reported to the department for episodes of clinical care and reflects the sex assigned at birth or early infancy as advised by the patient/clinician at that point of time. The sex at birth marker cannot be updated for a completed episode of clinical care and would generally not be updated at all unless correcting an administrative error.

For more information see the [reporting guides within the specifications for revisions to data collections for 2023-24](http://www.health.vic.gov.au/data-reporting/annual-changes) <www.health.vic.gov.au/data-reporting/annual-changes>

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|  ***Inclusive language for midwives and birth workers*** Getting language right can make a big difference to a family expecting a baby and set up a positive start to their parenting journey. While many people identify with the term ‘mother’, some people may prefer to be called ‘parent’, ‘birth parent’, ‘father’ or ‘pregnant person’. Trans and gender diverse people give birth too.Body talk comes up all the time in midwifery and birth work – when educating parents, during labour and birth, and supporting parents and babies postnatally. People may also use different terms for their anatomy. For example, some people may prefer the term ‘chest-feeding’ over breastfeeding. A good approach is to follow people’s lead when they talk about their own body.**Don’t assume, just ask in a respectful way if you’re unsure.**  |

# How to create a safe and affirming space for data collection

Collection of sex and gender information can be very sensitive for some trans and gender diverse people. A health service may be the first place a person discloses their gender identity, or one of few places where they disclose their sex assigned at birth. Some will have experienced non-inclusive data collection and discrimination in the past and may see data collection as sites of trauma.

## Create safer environments for disclosure

People are more likely to provide sensitive, personal information in a physically, emotionally, and culturally safe environment. Consider the following:

* What privacy might be available? Are there any private rooms or areas to fill out forms or have these discussions?
* A patient may feel uncomfortable or unsafe being ‘outed’ to your service or in front of strangers in the reception area. They may also be unable to be ‘out’ with people attending the reception area with them, such as parents, partners, or friends.
* Who is working in these spaces, and can a patient request to be supported by a LGBTIQA+ practitioner?

## Don’t make assumptions

It is important not to make assumptions about a person’s gender or sex based on how they look, sound, or their name. This can cause distress and may impact the accuracy of the data disclosed and collected.

If you are not sure about someone’s gender, use inclusive language, such as ‘they' or 'their' rather than 'he/she' or 'his/her'.

Do not assume the sex characteristics of your patient, such as anatomy or reproductive organs, based on the sex and/or gender field on a patient’s record. Some people may not have felt safe enough to disclose their sex assigned at birth and some people’s bodies do not fit the binary of male or female.

## Affirm your patient’s gender by using the right pronouns

If you’re unsure what someone’s pronoun is, ask them respectfully and preferably privately.

* Use a question like 'Can I ask what pronoun you use?'
* Do not ask 'What pronoun do you prefer?' A person’s pronoun and identity are not a preference.
* Do not only ask trans or gender diverse people, as this can single them out and potentially ‘out’ them.
* Consider sharing your own pronouns first. For example, ‘Hi, my name is Jack; my pronouns are they/them. What are your pronouns?’
* Consider sharing your pronouns in your email signature or name badge.

Misgendering is when you use incorrect pronouns about or towards a person.

## Informed disclosure: be prepared to provide information about privacy

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| *“If (health services) are opening spaces in data systems for trans people to disclose…this creates high anxiety for trans people who don’t want their identity known widely or accessed by a lot of people. There needs to be transparency and surety that that data is being used for specific purposes, in de-identified ways when used beyond that person’s care needs, and with strict confidentiality. The privacy and security should always be discussed with the person, so they*feel safe to disclose accurate information”Focus group participant, Transgender Victoria from the Final Insights Report: Diverse Communities Data Review Project 2022 |

Trans and gender diverse people may be concerned about the privacy, confidentiality, and security of their information in a society that is often openly hostile to trans and gender diverse people.

People may feel safer describing their sex and gender when they know this information will be treated respectfully and that there are systems in place to ensure that their privacy is protected.

Be prepared to share information about why the sex and gender data information is being collected and how it will be used, stored or shared with other staff, systems, and services.

Consider use of explanatory text boxes preceding a sensitive question on a form. For example, ‘This data will be [*aggregated/compiled/de-identified*] and may be used to count how many trans and gender diverse people are accessing the mental health system. This may be used to inform research, funding, policy, and best-practice.’

## Ask patients how they would like sensitive sex and gender information used or protected

It’s important to get your patient’s consent about how information about their sex and gender should be used or protected. You could ask your patient:

* What information about your identity can be shared with your family, friends and broader society?
* How would you like to be referred to when called in the waiting room?
* How would you like to be referred to in written correspondence and mail?
* Is there anything else you’d like us to be aware of?

It is useful to collect ‘disclosure safe-guarding’ details on an intake or patient data form to help other practitioners, clinicians, and administrators to support the needs of the patient in making their own choices around disclosure.

## Protect sensitive information in records and written communication

Design and update databases and information systems to capture name, pronouns, gender, sex at birth and current sex. Ensure that these database and information systems are secure, and that anyone who accesses them understands their obligations to protect sensitive sex and gender identity data.

Consider using alias fields where a patient wants to use one name in the health service or for correspondence but lives under a different name.

Consider flagging the ‘name’ or ‘sex at birth’ as ‘do not release’ for a trans or gender diverse patient with security concerns.

Ensure that all the information disclosed by a patient is correctly transferred at handover points between staff and in information systems. Be mindful of any data fields that are auto generated, for example to create a patient letter or referral.

## What if I make a mistake?

If you make a mistake, apologise, correct yourself and continue the conversation. Overemphasising or excessively apologising for your mistake can create further embarrassment, distress or frustration.

If you hear someone use the wrong pronouns, you can use words that gently inform or correct others about someone’s gender. For example, replying to ‘Alex has gone on her break’ with ‘Okay, we will see him when he’s back’.

Repeated or intentional mistakes show a lack of respect and can be very distressing. To deliberately misgender someone is a form of transphobia.

# Implementation advice for health services

Health services are expected to implement these changes in a way that is safe and inclusive for patients, supportive and empowering of staff, and that ensures accurate data capture for reporting and clinical care.

Consider including the following in your implementation plan:

* Tap into consumer and staff advisory networks to plan an implementation approach that meets everyone’s needs and brings people along the change journey.
* Review all data collection policies, forms and tools, interacting systems, and autogenerated documentation to ensure that patient’s gender will be affirmed in all health service communications to them and other providers.
* Provide clear advice and training for staff who are responsible for collecting patient information on how they can seek information and support.
* Discuss inclusive language with interpreters who support culturally and linguistically diverse patients. For more information, read the [LGBTIQ+ terminology factsheets in many languages](http://www.healthtranslations.vic.gov.au/resources/lgbtiq-terminology-in-your-language) <www.healthtranslations.vic.gov.au/resources/lgbtiq-terminology-in-your-language>
* Maintain consistency of data fields across your service’s data collection and data systems.
* Develop visual communication tools that explain the change to staff and community members, including to reduce the burden on administration staff. Consider placing visual communications in staff areas, administration areas and patient waiting areas around the hospital.
* Provide an avenue for patients and community members to share feedback on their experiences.
* Build in review points and share your implementation learnings with the department via Victorian Agency for Health Information (VAHI) or email Diversity and Access inbox at <diversity@health.vic.gov.au>.

# More information

## LGBTIQA+ resources

* [AusPATH](https://auspath.org.au/) (Australian Professional Association for Trans Health) <https://auspath.org.au/> – The national peak body for professionals working with trans and gender diverse people
* [Better Health Channel](https://www.betterhealth.vic.gov.au/health/healthyliving/transgender-and-transsexuality#bhc-content) <www.betterhealth.vic.gov.au/> – This site provides information on trans and gender diverse people
* [Community health LGBTIQ+ inclusive practice toolkit](https://www.health.vic.gov.au/community-health/community-health-pride-lgbtiq-inclusive-practice-resources) <www.health.vic.gov.au/community-health/community-health-pride-lgbtiq-inclusive-practice-resources> – Links to the toolkit to support LGBTIQA+ inclusive practice in Victorian community health services, pride posters and client flyers
* [Intersex Human Rights Australia](https://ihra.org.au) <https://ihra.org.au/> – A national body by and for people with intersex variations
* [Koori Pride Victoria](https://www.kooriepridevic.org.au/) <www.kooriepridevic.org.au/> – An organisation that supports the visibility, strength and connection for LGBTIQAS&B+ people across Victoria
* [Minus 18](https://www.minus18.org.au/articles/your-guide-to-words-and-definitions-in-the-lgbtqia%2B-community) (Guide to LGBTIQA+ words) <www.minus18.org.au/articles/your-guide-to-words-and-definitions-in-the-lgbtqia+-community> - Your guide to words and definitions in the LGBTQIA+ community
* [The Rainbow Tick](https://rainbowhealthaustralia.org.au/rainbow-tick) <https://rainbowhealthaustralia.org.au/rainbow-tick> – The Rainbow Tick is a quality framework that helps health and human services organisations show that they are safe, inclusive and affirming services for LGBTIQA+ communities
* [Transcend Australia](https://transcend.org.au/) <https://transcend.org.au/> – An organisation that supports trans and gender diverse young people and families
* [Transgender Victoria](https://tgv.org.au/) <https://tgv.org.au/> – An organisation supporting trans and gender diverse advocacy.

## Guides and standards for inclusive data collection

* [A guide to LGBTIQ+ inclusive data collection](https://genderrights.org.au/wp-content/uploads/2020/03/LGBTIQ-Inclusive-Data-Collection-a-Guide.pdf) <https://genderrights.org.au/wp-content/uploads/2020/03/LGBTIQ-Inclusive-Data-Collection-a-Guide.pdf> – A guide published by the Canberra LGBTIQA+ Community Consortium on how to collect inclusive data.
* [ABS 2020 Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables](https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release) – <www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release>The Australian Bureau of Statistics Standard which standardises the collection and dissemination of data relating to sex, gender, variations of sex characteristics and sexual orientation.
* [Department of Health Annual Change Process](https://www.health.vic.gov.au/data-reporting/annual-changes) <https://www.health.vic.gov.au/data-reporting/annual-changes> - This webpage outlines the Department of Health’s latest review of the data elements and format of key health services data collections.
* [LGBTIQ+ Inclusive Language Guide](https://www.vic.gov.au/inclusive-language-guide) (published by Victorian State Government) –<www.vic.gov.au/inclusive-language-guide> - An inclusive language guide for Victorian Public Sector (VPS) employees who work with and refer to LGBTIQA+ people.

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