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Care Considerations for Inclusion of Gender Diversity within Medical Laboratory Services



Institute for Quality
Management in Healthcare



Scope of this presentation

Heart

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Understanding

Science

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Reference Intervals

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Sex vs Gender

- Historically, these have been used interchangeably, but they are different
- Genetic factors define the sex of an individual. Even this is not strictly binary
- Gender is social and cultural role
- Canadian Institute of Health Research definition:

Gender refers to the socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people. It influences how people perceive themselves and each other, how they act and interact, and the distribution of power and resources in society. Gender is usually conceptualized as a binary (girl/woman and boy/man) yet there is considerable diversity in how individuals and groups understand, experience, and express it.



Source: Duane Brayboy

Did you know?

- At the time when Europeans arrived in North America, all Native American societies acknowledged three to five gender roles.
- Traditionally, Two Spirit people earned great respect.
- Each tribe has their own specific terms, but there was a need for a universal term that the general population could understand: Two Spirit
- George Catlin reported back to England that the Two Spirit tradition among Native Americans “Must be extinguished before it can be more fully recorded.”

Bill C-16

- In Canada, all territories and provinces recognize gender identity and expression as a protected human right
- In 2017, Bill C-16 become law guaranteeing gender identity and expression as protected human rights federally
- This has allowed transgender Canadians to make legal name and ID changes; including passports

Source: Canadian Human Rights Act

HOUSE OF COMMONS OF CANADA

BILL C-16

An Act to amend the Canadian Human Rights Act and the Criminal Code

FIRST READING, MAY 17, 2016

MINISTER OF JUSTICE

90796

SUMMARY

This enactment amends the *Canadian Human Rights Act* to add gender identity and gender expression to the list of prohibited grounds of discrimination.

The enactment also amends the *Criminal Code* to extend the protection against hate propaganda set out in that Act to any section of the public that is distinguished by gender identity or expression and to clearly set out that evidence that an offence was motivated by bias, prejudice or hate based on gender identity or expression constitutes an aggravating circumstance that a court must take into consideration when it imposes a sentence.

Terms to Know

LGBTQ2S+ / LGBTQ* / LGBTQ+

Acronym for “lesbian, gay, bisexual, transgender, queer/questioning, two-spirit.” Sometimes “*” or “+” is used at the end to represent the many diverse sexual orientations and gender identities that are part of this community

Cisgender/Cis

A person whose gender matches the sex they were assigned at birth.



Terms to Know

Gender Expression

External and public presentation of a person's gender expressed through an individual's name, pronouns, clothing, haircut, behaviour, voice, or body characteristics.

Gender Identity

One's internal, deeply held sense of one's gender. For transgender people, their own internal gender identity does not match the sex they were assigned at birth. Some people may not identify with a gender at all. Unlike gender expression, gender identity is not visible to others.



Terms to Know

Transgender (Trans, Trans-identified)

People whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth.

Transition

The process of a transgender individual who publicly changes their gender presentation is known as “transitioning.”



Terms to Avoid

Transgenderism

A term used by anti-transgender activists to dehumanize transgender people and reduce who they are to a “condition.”

Transgendered (verb), Transgender (noun)

Using transgender as a verb suggests that being transgender is something that happened to a person rather than reflecting who they actually are. For example, we don't say “John Smith is a gayed man”, therefore; we wouldn't say “Joanne Smith is a transgendered woman.”

Similarly, we wouldn't use transgender as a noun. For example, we wouldn't say “we have many transgenders who work here” nor would we say “she is a transgender.”

The word transgender should only be used as an adjective as in “Joanne Smith is transgender woman.”

Ethical Considerations

Gender diverse persons, particularly those who identify as transgender, have been medically underserved & marginalized.

They face discrimination, prejudice and stigma

Healthcare avoidance may be pronounced

Ethical Considerations

Lack of awareness & preparation stems in part from inaccurate assumptions of the size of the gender diverse populations

It is assumed that trans people can be dealt with on an individual basis. As a result, when a trans or gender diverse patient accesses healthcare, clinicians and healthcare teams are unprepared to offer nuanced care.

The number of trans and gender-diverse persons in Canada have been conservatively estimated to be 0.6 % of the population, extrapolated to 2016 Canadian census counts — 200,000 trans individuals aged 18 and older in Canada

Requisitions and Information Systems

Most institutions do not have policies, processes, or the informational technology (IT) functionality to collect, store, or display gender identity data.

While legal name and sex are often required for billing or other purposes, the ability to capture information that allows the patient to be addressed in the manner they choose will greatly improve their healthcare experience.

Options to clarify non-binary genders on the laboratory requisition can facilitate improved healthcare.

Fenway Institute Two- Step Process

What sex were you assigned at birth on your original birth certificate?

- Male
- Female
- Decline to Answer

Do you think of yourself as:

- Male
- Female
- Female-to-Male (FTM)/Transgender Male/Trans Man
- Male-to-Female (MTF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Additional gender category/(or Other), please specify: _____
- Decline to Answer

How does this apply to lab requisitions?

The Fenway 2-step process may not be practical or necessary for lab requisitions.

One solution could be to allow space for the following three selections:

- Sex at birth
- Administrative/legal gender (needed for billing purposes)
- Gender identity (if different from administrative/legal gender) (optional)
- Sex at birth and legal gender can serve as an indication of gender incongruence and either can be used as a guide for laboratory interpretation and reporting.
- Legal gender is also often needed for billing purposes.
- Gender identity can be offered as “optional” and serve to facilitate quality patient interactions by alerting specimen collection and laboratory staff to ask appropriate questions

Additional Information

- Collecting gender identity, preferred name, and pronouns (even in the absence of changes to information systems and requisitions) is the best interim solution to provide inclusive care to individuals with diverse gender identities.
- This can be done by having the patient answer questions in a private space, by filling out a form for laboratory or hospital staff to transcribe, or by allowing the patient to self-register either through a web portal or self-serve kiosk. The latter two are preferred unless the questions can be asked discretely as to ensure the privacy of the patient.

Inclusive Environments

Specimen collection centres are the main site of direct interaction of individuals with laboratory staff and services, and as such play a crucial role in reflecting gender diverse spaces.

Offer gender-neutral spaces, including hospital rooms and restrooms, in all areas of the hospital;

Health care providers to ask sensitive questions in private spaces only;

Consider solutions to avoid calling out names in group areas, and never use prefixes or honorifics (Mr/Mrs/Miss), e.g. alpha-numeric queue system.

Patient Communication

A simple interaction can be complicated by an employee uncertain with how to handle gender incongruence — the name on the patient's health card and/or requisition may not match the physical presentation of the patient.

Assumptions regarding gender identity can potentially lead to confusion and negative experiences for both the patient and the laboratory staff.

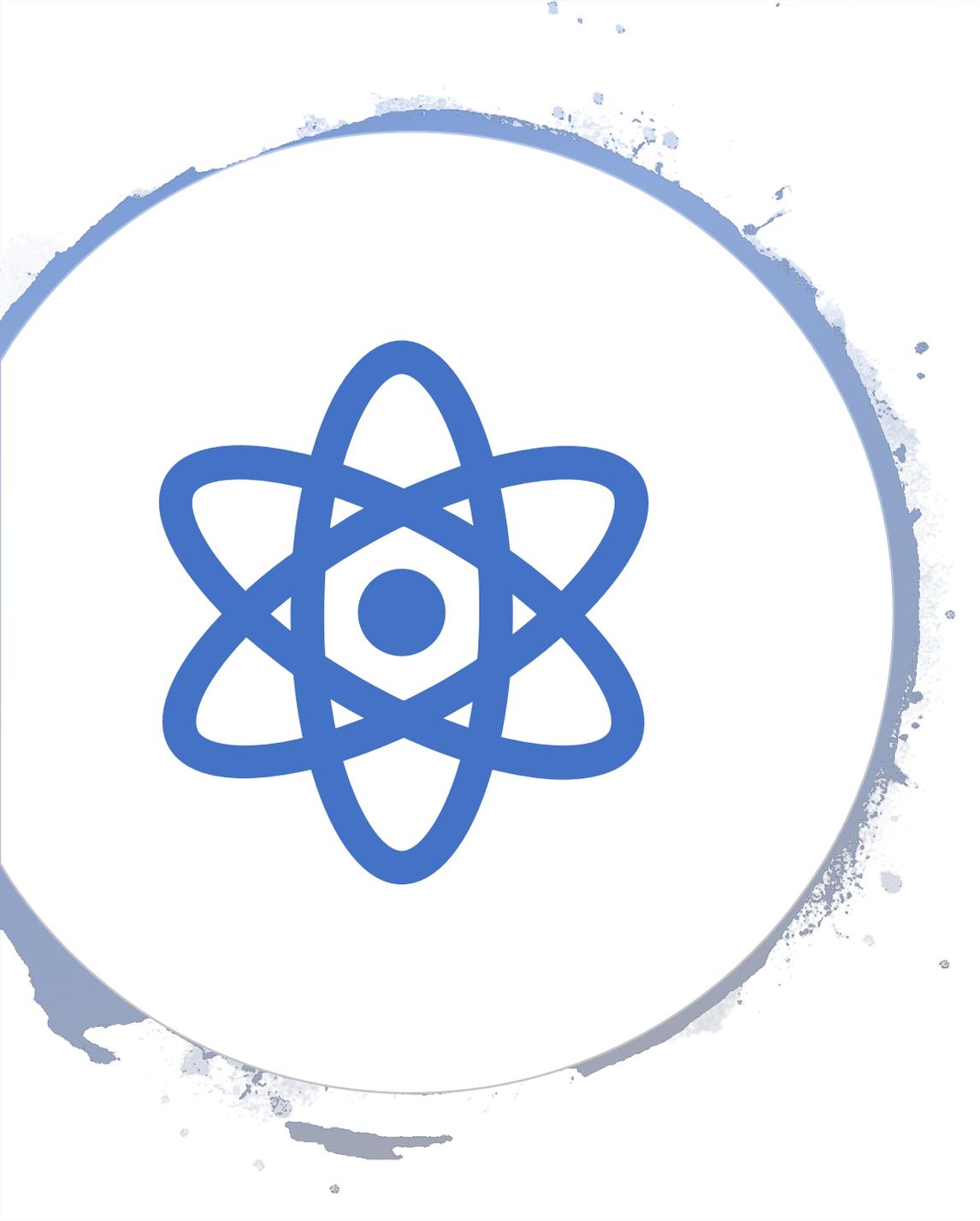
Efforts ought to be presented as a choice for patients as opposed to forcing identification of sensitive data, particularly around gender identity and sexual orientation.

Patient Communication

Following initial communication where name and/or pronouns and gender identity have been clarified, a system should be in place to notify subsequent providers and staff of a patient's correct name and/or pronouns.

Systems should include a recognizable notation or bolding of correct name that conveys to the intended staff of the appropriate information and how to utilize it, but in a way that does not label patients and further stigmatize them.

Patients who are repeatedly having to reorient themselves to new staff and possibly re-educate each new person, will experience fatigue and frustration



Scientific Considerations

Example One

Delayed kidney transplant intervention in a transgender man.

In this case, the estimated glomerular filtration rate was used according to clinical guidelines for male patients, in spite of patient's small stature, vegan diet, and female sex at birth, all of which influence creatinine level used to calculate eGFR.

This led to delayed transplantation and prolonged patient suffering.

Example Two

Advanced cervical cancer in a transgender male due to lack of appropriate medical advice on cervical cancer screening by Papanicolaou (pap) smear.

Laboratory Testing

- There is paucity of data on transgender laboratory result interpretation due to a lack of large-cohort studies but those that have been conducted show that hormone therapy does not simply result in laboratory values that switch to match the reference interval of the gender identity of the individual.
- The largest study included 183 transgender women and 119 transgender men and found that the impact of hormone therapy is not always predictable.
- The study concluded that “Some laboratory values changed to match the gender identity, whereas others remained unchanged or were intermediate from baseline values.”

It is never an abrupt change: It's NOT binary

During transition, marker levels may change over time

Additionally, differences may exist based on hormone treatment modalities, age at the onset of treatment or due to non-standardized methods and non-harmonized reference intervals among laboratories.

Therefore, defining “normal” marker levels in transgender individuals adds to the known complexity laboratories face when determining reference intervals in diverse demographic groups

Complexity

A gender non-binary patient's legal gender may differ from sex at birth, but this does not imply the patient is undergoing hormone therapy.

Reporting reference intervals corresponding to the patient's sex at birth is suggested as this may be the best reflection of the patient's physiology.

Moreover, as previously stated, reference intervals are not available for gender diverse individuals undergoing hormone treatment or who have had physiology altering surgery.

IQMH Working Group Recommendations

- The IQMH Working Group suggests that labs report the reference intervals that correspond to the patient's sex at birth.
- A comment could be added to all reports to inform users that the reference intervals reported may not apply to all patients.
For example: "As different demographic populations can be very physiologically diverse (e.g. gender non-binary individuals), reference intervals provided on this report may not apply to all patients."
- Labs should consider providing health care providers with guidance on to interpret tests on gender non-binary patients undergoing hormone therapy treatment or who have had physiology altering surgery.
- Due to the paucity of literature on RI for transgender patients, clinicians will need to use clinical judgement in interpretation

IQMH Working Group Recommendations

- Labs should not cancel tests based on sex (e.g. hCG, PSA, Pap smear). Tumour markers and pregnancy tests should be performed without sex specificity.
- Ensure cytology and histology staff expect the possibility of receiving tissue samples from transgender persons.
- Ensure genetic testing is not cancelled due to mismatch of the test requested with the patient identifiers.
- For certain genetic tests it may be necessary to collect information on an individual's sex at birth to ensure the accurate interpretation of genetic test results.
- Transfusion policies should include issuing type O, Rh negative blood to any individual with assumed ability to become pregnant.

Compassion and Inclusion First

- While it may seem disappointing that we cannot yet pin down reference intervals for this population, it was the only logical conclusion.
- Wanting to definitively stratify into female or male is a failure to recognize the fluid nature of transition
- **Perhaps the stratification of reference intervals by sex is equally flawed for cis-gender individuals**
- The first step is education and providing gender-affirmative care
- Get the terms right. Stop making assumptions. Make an effort with pronouns

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