



GENDER & SEX:  
A BRIEF DISCUSSION OF  
OPERATIONALIZATION IN  
HEALTH CARE

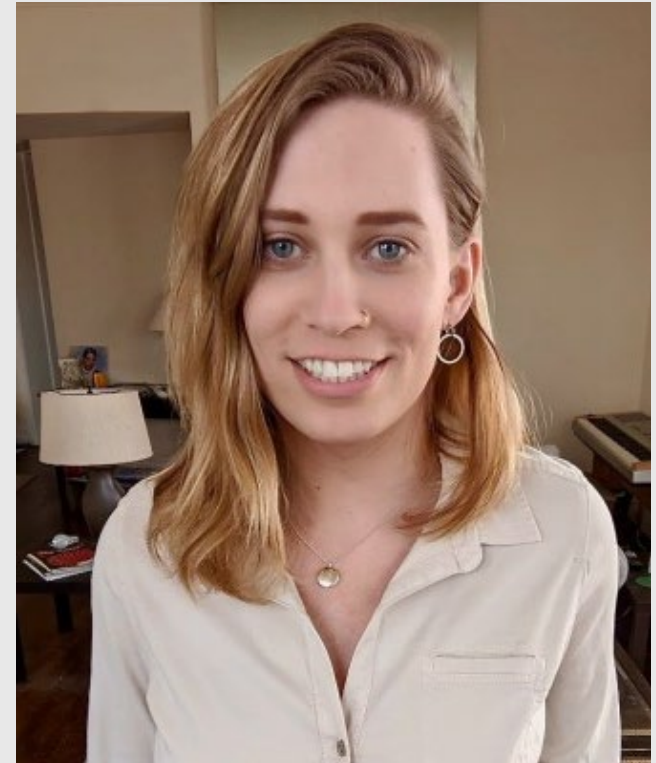
Clair Kronk, PhD (she/her)  
([clair.kronk@yale.edu](mailto:clair.kronk@yale.edu))  
24 February 2022

# Disclosures

- I have no disclosures.

# About Me

- Postdoctoral fellow at Yale University.
- Thesis focused on the Gender, Sex, and Sexual Orientation (GSSO) ontology, a vocabulary of over 14,000 LGBTQIA+-related terms (part of the OBO Foundry, available here: <http://www.ontobee.org/ontology/GSSO>).
- Consultant for Canada Health Infoway, DICOM, HL7, OutHistory, Queensland Health, and SNOMED CT.
- Board member at Homosaurus, the Trans Metadata Collective, and AMIA Inclusive Language Guidelines Task Force.



# The Good, The Bad, and the Ugly (But Mostly the Ugly)

\* Gender:

Does the Beneficiary reside a

\* Contact Phone:

- Female
- Male
- N/A
- Unknown
- Tax Entity

Gender:

Female

Female

Male

Hot Bread

ary

2013

Email:

Male

Please select gender

Male

Female

Venezuela

Choose One

Male

Female

Transgender

Declined

What is your gender?

Female

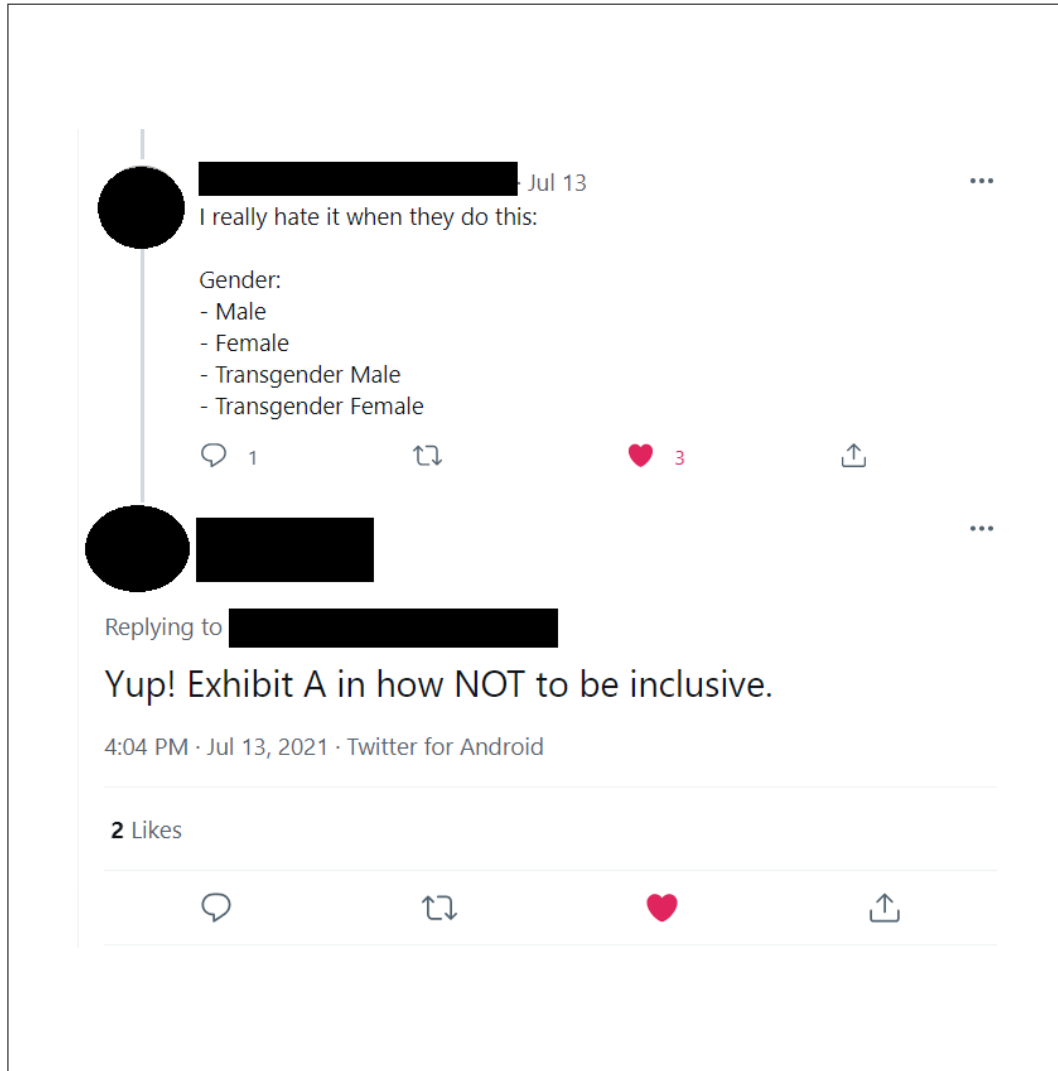
Male

Cisgender/Non-binary

Prefer to not answer

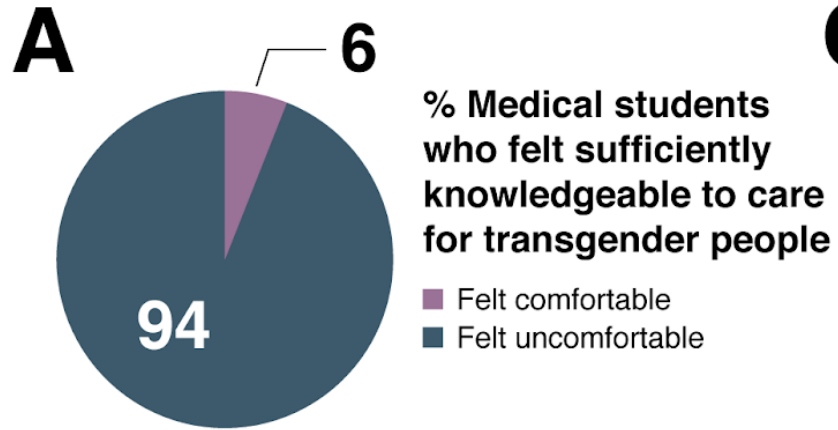
# The Good, The Bad, and the Ugly (But Mostly the Ugly)

- Trans and gender diverse people: have you ever had an issue with choosing options for “gender” on a survey, intake form, or other questionnaire? (1,333 respondents; run 19 October 2020)
  - Yes [94%]
  - No [6%]
- Does separating male/female and trans male/trans female on surveys and forms imply that male/female is “normal” and trans male/trans female is “deviant”? (401 respondents, run 11 January 2021)
  - Yes [84%]
  - No [16%]

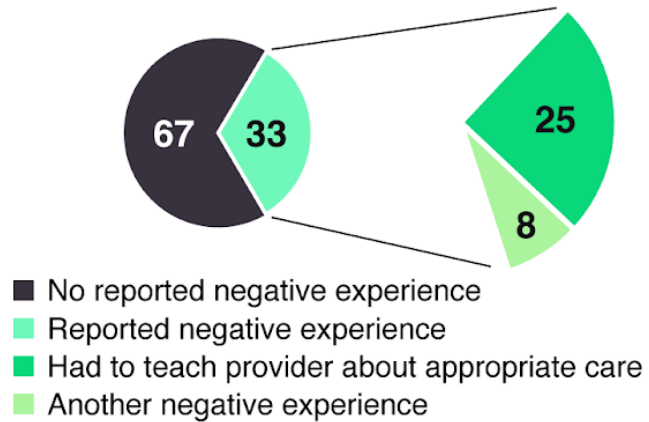


# Designing Systems for Clinical Use

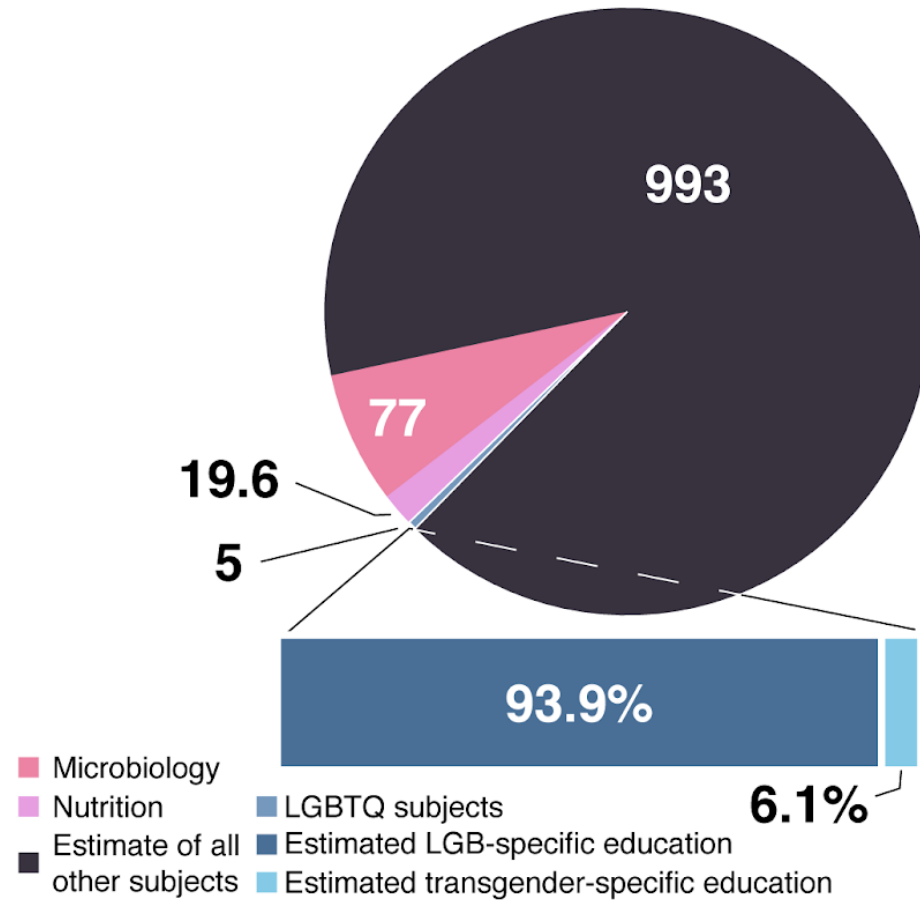
- Systems should align with standards in order to be functional.
- Systems should align with patient care needs.
- Systems should be usable and understandable to clinicians.
- **Systems should be designed for care first**, everything else second.
- Design for the *most* vulnerable patients, not the most privileged.
- Have a baseline level of respect for patients in data.
- Realize and take into account current state—if your system can't be added to patient intake forms or be easily into current electronic health systems, then its effectively useless.



**B** **% Transgender patients who reported having a negative experience with a health care provider within the last year**



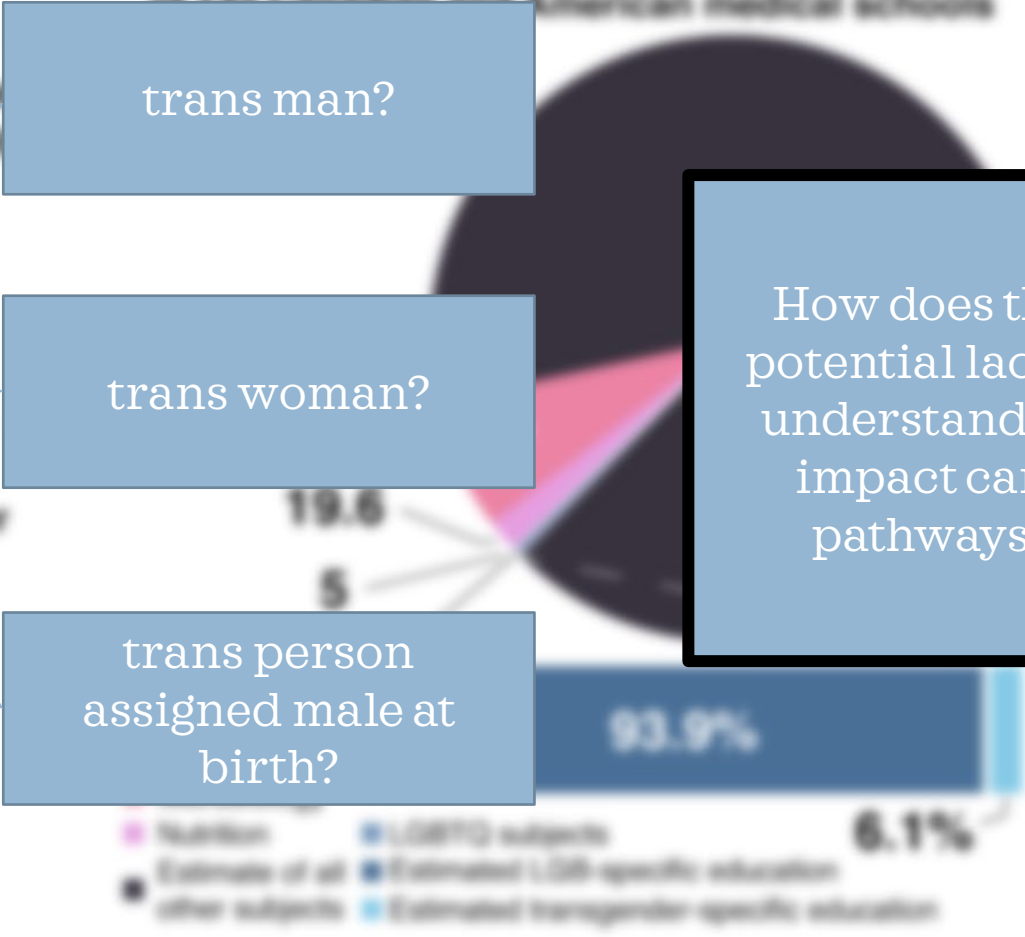
**C** **Hours of LGBTQ education reported among deans of 132 Canadian and American medical schools**







**C** Hours of LGBTQ education reported among deans of 100 Canadian and American medical schools



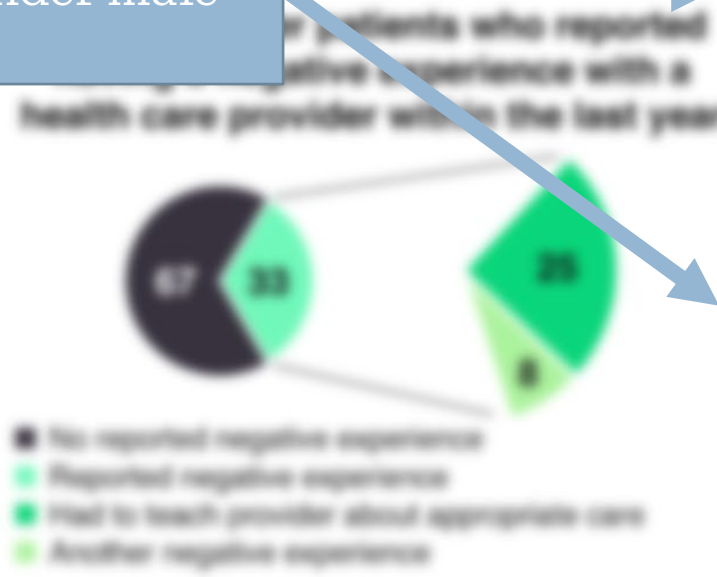
“transgender male”

trans man?

trans woman?

trans person assigned male at birth?

How does this potential lack of understanding impact care pathways?





Marker	Misinterpretation Risk(s) When Incorrect Reference Ranges Are Used
Alb:creatinine ratio	Errors in diagnosis of microalbuminuria.
CA 125	Errors in diagnosis of ovarian malignancy.
Creatinine	Errors in diagnosis of kidney disease.
Ferritin	Errors in diagnosis of iron deficiency and/or overload.
HCG	Errors in diagnosis of testicular malignancy.
HDL	Errors in estimating cardiovascular risk.
Hematocrit	Errors in diagnosis of anemia and/or polycythemia.
Hemoglobin	Errors in diagnosis of anemia and/or polycythemia.
Iron	Errors in diagnosis of iron deficiency and/or overload.
PSA	Errors in diagnosis of prostate cancer and/or hyperplasia.
RBC count	Errors in diagnosis of anemia and/or polycythemia.
Troponin I	High risk of errors in diagnosis of myocardial infarct and/or acute coronary syndrome.
Urate	Errors in diagnosis of gout.
Urinary creatinine	Could impact any 24-hour urine investigation, including, but not limited to, metadrenalines (pheochromocytoma), cortisol (Cushing syndrome), and 5HIAA (carcinoid syndrome).

From narrative review in progress, email for details.

Variable	Gender Modality	AGAB	Hormone Status	Surgical Status	Other Condition	Range Suggested
ALP	Trans	M	Estradiol (>6 months)	Any	N/A	Male
Creatinine	Trans	M	Estradiol (>6 months)	Any	N/A	Male
eGFR	Trans	F	None or Testosterone (<3 months)	Any	N/A	Female
eGFR	Trans	F	Testosterone (>3 months)	Any	N/A	Male
eGFR	Trans	M	None or Estradiol (<3 months)	Any	N/A	Male
eGFR	Trans	M	Estradiol (>3 months)	Any	N/A	Female
Hemoglobin	Trans	F	Testosterone (>12 months)	Any	N/A	Male
Hemoglobin	Trans	M	Estradiol (>6 months)	Any	N/A	Female
Hematocrit	Trans	F	Testosterone (>12 months)	Any	N/A	Male
Hematocrit	Trans	M	Estradiol (>6 months)	Any	N/A	Female
Iron	Trans	F	Any	Any	If menstruating or pregnant.	Female
Iron	Trans	F	Testosterone	Any	If amenorrhoeic and not pregnant	Male
K+	Trans	M	Estradiol (>6 months)	Any	N/A	Male
LDL	Trans	M	Estradiol (>6 months)	Any	N/A	Female
RBC Count	Trans	F	Testosterone (>12 months)	Any	N/A	Male
RBC Count	Trans	M	Estradiol (>12 months)	Any	N/A	Female
Triglycerides	Trans	M	Estradiol (>6 months)	Any	N/A	Neither
Troponin I	Trans	F	Any	Any	N/A	Female
Troponin I	Trans	M	Any	Any	N/A	Male

From narrative review in progress, email for details.

Variable	Gender Modality	AGAB	Hormone Status	Surgical Status	Other Condition	Range Suggested
ALP	Trans	M	Estradiol (>6 months)	Any	N/A	Male
Creatinine	Trans	M	Estradiol (>6 months)	Any	N/A	Male
eGFR	Trans	F	None or Testosterone (<3 months)	Any	N/A	Female
eGFR	Trans	F	Testosterone (>2 months)	Any	N/A	Male
eGFR	Trans	M				Male
eGFR	Trans	M				Female
Hemoglobin	Trans	F				Male
Hemoglobin	Trans	M				Female
Hematocrit	Trans	F				Male
Hematocrit	Trans	M				Female
Iron	Trans	F			Quitting or pregnant.	Female
Iron	Trans	F			Menorrhoeic and not pregnant	Male
K+	Trans	M				Male
LDL	Trans	M				Female
RBC Count	Trans	F	Testosterone (>12 months)	Any	N/A	Male
RBC Count	Trans	M	Estradiol (>12 months)	Any	N/A	Female
Triglycerides	Trans	M	Estradiol (>6 months)	Any	N/A	Neither
Troponin I	Trans	F	Any	Any	N/A	Female
Troponin I	Trans	M	Any	Any	N/A	Male

Clinical decision making cannot be made using solely gender identity or assigned gender at birth.

Doing so can cause irreparable harm or even death.

# Clinical Standards Systems

- Health Level 7 Gender Harmony Project
  - **Sex for Clinical Use (SFCU)**
  - **Gender Identity**
  - **Recorded Sex or Gender (RSG)**
  - Name to Use
  - Third-Person Pronouns

# Sex for Clinical Use (SFCU)

- In the clinical setting, occasionally there are rules in the electronic health record which include “sex” or “gender” as a variable, but with no explanation as to what that *actually* refers to:  
Gender identity? Karyotype? Organ makeup? Assigned gender at birth? Gender with a health insurance provider? Who knows!
- Untangling this is a messy, potentially multi-billion dollar process; so in the meantime, HL7 has suggested usage of “sex for clinical use”, a datum which describes a procedure, diagnostic, laboratory result, reference range, imaging specification, etc.

# Gender Identity

- Whenever you see the words “gender” or “sex” on a form, and a source document isn’t specified, usually we are talking about gender identity
- All people have a gender identity, not just transgender people
- Understanding of gender identity can change over a lifetime; some people have more than one simultaneously; and some people reflect different gender identities in different scenarios for safety reasons
- For cisgender and transgender women, gender identity is usually female
- For cisgender and transgender men, gender identity is usually male
- Nonbinary, bigender, demigender, trigender, pangender, and neutrois represent a handful of other gender identities
- Some labels like Two-Spirit may encompass gender identity or may not
- Sometimes gender identities overlap, such as for people who identify as nonbinary and female, as hijra and female, or as Two-Spirit and male

# Recorded Sex or Gender (RSG)

- Currently, EHR systems include an “AdministrativeGender” which has been left undefined by standards organizations, on purpose
- Every jurisdiction, every clinic, every hospital, every EHR system defines this completely differently
- Recorded Sex or Gender was created to tease out everything that isn't a gender identity or a sex for clinical use
- Some examples of RSG:
  - Assigned gender at birth (AGAB) as the gender marker on your birth certificate or other birth record
  - The gender marker registered with your health insurance or vehicle insurance
  - The gender marker on a passport, driver's license, or visa



# Linguistic Considerations

- Always take into account linguistic drift—will a term mean the same thing in 5 years? 10 years?
- Prioritize terminology which is consistent, understandable, and translateable.
- Does the question match the answers?
- Consider clarifying terms sparingly.

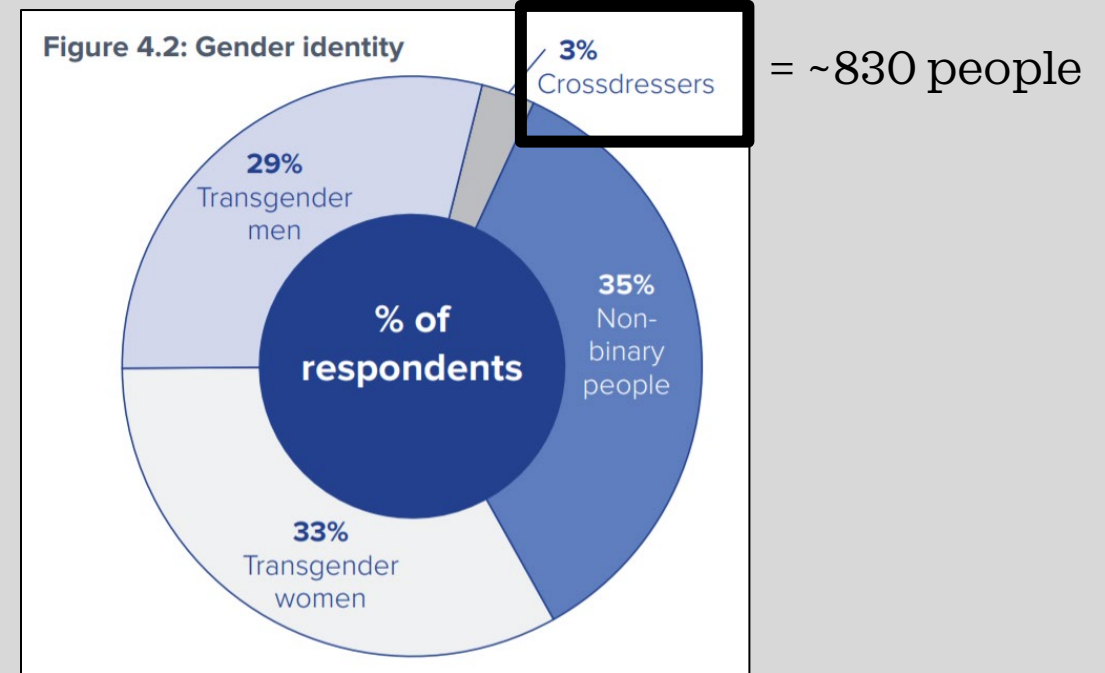
# Linguistic Drift in Sexual Orientation Measurement

- Dr. Randall Sell found that there was a significant lack of understandability of “heterosexual” and “straight” among older heterosexual people in the 1990s.
- This led to a “Heterosexual (Not gay or lesbian)” option which is still in use today.
- However, there has not been a reassessment of understanding. “Heterosexual” and “straight” are now considered highly known concepts.
- Should we still be including this option? How often should reassessments be performed? Can we easily operationalize reassessments?



# What does 'transgender' mean?

- **The most cited trans survey of all time is the 2015 United States Transgender Survey (USTS)**
  - Have you ever wondered why so many self-described cross-dressers answered the survey?



# What does 'transgender' mean?

## 1988

“It used to be that a 'transgender[ist]' was a person who could express him or herself comfortably in both masculine and feminine terms... Recently, however, the term 'transgender[ist]' has come more and more to mean a person of one sex living entirely in the gender role generally considered appropriate for the opposite sex (cross-living). Most people who consider themselves to be transgender[ists] do not want or need sexual reassignment surgery, and do not identify with 'transvestite’.”

## 1998

“Originally, transgender referred to the group of people, also know[n] as full-time cross-dressers or nonsurgical transsexuals, who live and work as the opposite gender continuously and for always. Now it more often refers to the group of all people who are inclined to cross the gender line, including both cross-dressers and gender-benders, the 'umbrella definition' that covers everyone.”

# What does 'transgender' mean?

## 2008

“An umbrella term for people whose gender identity and/or gender expression differs from the sex they were assigned at birth. The term may include but is not limited to: transsexuals, cross-dressers, and other gender-variant people. Transgender people may identify as female-to-male (FTM) or male-to-female (MTF). Use the descriptive term (transgender, transsexual, cross-dresser, FTM or MTF) preferred by the individual. Transgender people may or may not decide to alter their bodies hormonally and/or surgically.”

## 2018

“Often shortened as ‘trans’. An umbrella term for people whose gender and/or expression does not match their birth assignment. Transgender includes many of the terms in this list and may or may not include transsexuals, cross dressers, drag kings/queens, and others who defy what society tells them their gender should be. How people identify with this term depends on the individual and their relationship with their gender.”

# Introducing Gender Modality

- Lack of consistency inherently makes any comparative surveys or studies asking if a person identifies as ‘transgender’ unreliable and ungeneralizable.
- The solution? Moving toward more consistent measures, like *gender modality*.
- Ashley (2019) defined gender modality as “how a person’s gender identity stands in relation to their gender assigned at birth”.
- We can easily operationalize gender modality using a two-step, which maximizes avoidance of linguistic shift.

# Defining 'Transgender' Consistently

- Under this model, transgender populations would be defined using an incongruence between *gender identity* and *assigned gender at birth*, referencing transgender as a form of gender modality in clinical care.
- This option works well in international contexts, with known models of linguistic drift, and consistent terminological knowledge which has high penetration in most subpopulations.



# Defining ‘Intersex’

- Intersex has a much more consistent definition than transgender, in regard to the definition as a congenital condition.
- However, there is no community or provider consensus on what conditions *are* or *are not* intersex.
- For purposes of care and research, this makes lists of conditions more reliable than any individual question could be.
- Most intersex people agree that intersex is not a gender identity, and legally, it is almost never an assigned gender at birth.
- Some intersex people are cisgender and some are transgender. Individuals may use different gender modality terms which do not yet have wide enough traction to be clinically useful (*ipsogender* and *ultergender*), but this may change.
- For more information, see interACT’s [“Intersex Data Collection: Your Guide to Question Design”](#).

# A Non-Exhaustive List of Conditions Which May Be Considered Intersex

- 5 $\alpha$ -reductase deficiency
- 17 $\beta$ -hydroxysteroid dehydrogenase-3 deficiency
- Androgen insensitivity syndrome
- Ambiguous genitalia
- Aphallia
- Bladder extrophy
- Congenital adrenal hyperplasia
- Clitoromegaly
- Cryptorchidism
- De la Chapelle syndrome
- Epispadias
- Fraser syndrome
- Genetic mosaicism
- Gonadal dysgenesis
- Hypospadias
- Jacobs syndrome
- Kallmann syndrome
- Klinefelter syndrome
- Leydig cell hypoplasia
- Late onset adrenal hyperplasia
- micropenis
- Mayer-Rokitansky-Küster-Hauser syndrome
- Mullerian aplasia
- Ovotestes
- Persistent Mullerian duct syndrome
- Progestin induced virilization
- Swyer syndrome
- Turner syndrome

## METHOD 1: ONE-STEP

### Example A

Do you consider yourself transgender? *Choose one.*

- Yes
- No
- Unsure; Maybe; Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Something else (please specify)

### Example B

Does your gender identity match the gender you were assigned at birth? *Choose one.*

- Yes
- No
- Unsure; Maybe; Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Something else (please specify)

## METHOD 2: TWO-STEP

What is your gender identity? *Choose all that apply.* [note 1]

- Female; Woman; Girl
- Male; Man; Boy
- Nonbinary
- Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Gender identity not listed (please specify)

What is your assigned gender at birth, meaning the gender marker which appears on your original birth certificate? *Choose one.* [note 2]

- Female ('F')
- Male ('M')
- X [note 3]
- Unsure
- Prefer not to respond; Prefer not to disclose
- Assigned gender at birth not listed (please specify)

- Document written by 17 trans authors representing bioethics, biomedical informatics, biostatistics, family medicine, law, neuroscience, nursing, physiology, psychiatry, public health, social policy, social work, and social welfare.
- Feedback was solicited over 10 months from TPATH (~1,100 members) and the Trans PhD Network (~1,900 members), as well as via surveys of more than 2,000 trans Twitter users.
- We recommended the two-step to the left as a baseline for medical practice, with notes considering usage in relationship to particular communities.
- This model aligns with HL7's current balloting process, and guidelines considering birth certifications and registries.

Preprint available here: <https://doi.org/10.31235/osf.io/qnc2g>

## METHOD 1: ONE-STEP

### Example A

Do you consider yourself transgender? *Choose one.*

- Yes
- No
- Unsure; Maybe; Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Something else (please specify)

### Example B

Does your gender identity match the gender you were assigned at birth? *Choose one.*

- Yes
- No
- Unsure; Maybe; Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Something else (please specify)

## METHOD 2: TWO-STEP

What is your gender identity? *Choose all that apply.* [note 1]

- Female; Woman; Girl
- Male; Man; Boy
- Nonbinary
- Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Gender identity not listed (please specify)

What is your assigned gender at birth, meaning the gender marker which appears on your original birth certificate? *Choose one.* [note 2]

- Female ('F')
- Male ('M')
- X [note 3]
- Unsure
- Prefer not to respond; Prefer not to disclose
- Assigned gender at birth not listed (please specify)

- This model is just a start for recommendations, **it is not an end-all be-all, nor should it be.**
- Specific communities and areas should assess needs from local groups, such as with Two-Spirit and Māhū individuals, for accessibility and usefulness.
- Needs analysis should be performed relatively consistently.
- Feedback options and explanations for why data are collected in this manner should not be an afterthought.

Preprint available here: <https://doi.org/10.31235/osf.io/qnc2g>

# Connecting the Two-Step to the Gender Harmony Project

Transmitted using the HL7 / USCDI v2 datum “Gender Identity”

Transmitted using the HL7 datum “recorded sex or gender” with document type noted as “birth certificate” (can be reworked to be any document, per a region’s preferences).

## METHOD 2: TWO-STEP

**What is your gender identity? Choose all that apply.** [note 1]

- Female; Woman; Girl
- Male; Man; Boy
- Nonbinary
- Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Gender identity not listed (please specify)

**What is your assigned gender at birth, meaning the gender marker which appears on your original birth certificate? Choose one.** [note 2]

- Female ('F')
- Male ('M')
- X [note 3]
- Unsure
- Prefer not to respond; Prefer not to disclose
- Assigned gender at birth not listed (please specify)

## Connecting the Two-Step to the Gender Harmony Project

### METHOD 2: TWO-STEP

What is your gender identity? *Choose all that apply.* [note 1]

Female; Woman; Girl

Male; Man; Boy

Nonbinary

Questioning; Exploring

Prefer not to respond; Prefer not to disclose

Gender identity not listed (please specify)

What is your assigned gender at birth, meaning the gender marker which appears on your original birth certificate? *Choose one.* [note 2]

Female ('F')

Male ('M')

X [note 3]

Unsure

Prefer not to respond; Prefer not to disclose

Assigned gender at birth not listed (please specify)

**Incongruence can be used as a quick proxy for trans cohort creation, and congruence can be used for cis cohort creation.\***

Transmitted using the HL7 / USCDI v2 datum "Gender Identity"

Transmitted using the HL7 datum "recorded sex or gender" with document type noted as "birth certificate" (can be reworked to be any document, per a region's preferences).

\*Gold standard is still patient self-identification as "transgender," but incongruence casts larger, more consistent, net

## Connecting the Two-Step to the Gender Harmony Project

Transmitted using the HL7 / USCDI v2 datum "Gender Identity"

**Gender Identity** → {  
Gender  
Validity Period  
Comment  
}

Transmitted using the HL7 datum "recorded sex or gender" with document type noted as "birth certificate" (can be reworked to be any document, per a region's preferences).

**Recorded Sex or Gender** → {  
Source Recorded Sex or Gender  
International Equivalent Recorded Sex or Gender  
Record Description  
Acquisition Date  
Validity Period  
Jurisdiction  
Source Field Name  
Source Field Description  
}



## Connecting the Two-Step to the Gender Harmony Project

Can be used to indicate periods of gender fluid or other shifting identities.

**Gender Identity** → {  
Gender  
Validity Period  
Comment

Could be used to indicate privacy considerations or other concerns, such as if an individual is not out in particular settings.

**Recorded Sex or Gender** → {  
Source Recorded Sex or Gender  
International Equivalent Recorded Sex or Gender  
Record Description  
Acquisition Date  
Validity Period  
Jurisdiction  
Source Field Name  
Source Field Description  
}

## Connecting the Two-Step to the Gender Harmony Project

Used to record exactly as the value appears in the source.

```
Gender Identity → {  
  Gender  
  Validity Period  
  Comment  
}
```

Used if an equivalent is needed in international settings, databases, software, etc.

```
Recorded Sex or Gender → {  
  Source Recorded Sex or Gender  
  International Equivalent Recorded Sex or  
  Gender
```

'Birth certificate' could be indicated here.

```
  Record Description  
  Acquisition Date  
  Validity Period  
  Jurisdiction
```

Assigned gender at birth would likely be indicated here.

```
  Source Field Name  
  Source Field Description  
}
```

# Why even include a “one-step”?

## METHOD 1: ONE-STEP

### Example A

Do you consider yourself transgender? *Choose one.*

- Yes
- No
- Unsure; Maybe; Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Something else (please specify)

### Example B

Does your gender identity match the gender you were assigned at birth? *Choose one.*

- Yes
- No
- Unsure; Maybe; Questioning; Exploring
- Prefer not to respond; Prefer not to disclose
- Something else (please specify)

- While the biomedical benefits of the two-step are clear, assigned gender at birth is private information that should be protected.
- Usage of the two-step on sociological studies, government studies and censuses, employment forms, and the like may at best, have little relevance, and, at worst, be actively harmful. In these cases, a one-step, with explanation as to how the data will be used and protected may be more applicable.

# Organ Inventories, Genetic Screenings, Hormonal Profiles, Names to Use, and Pronouns: A Brief Aside

- Pronouns and Names to Use are essential for clinical interactions to prevent misgendering and misnaming
  - We do not have a lot of international linguistic data for implementation of some of these; for example, some languages do not have pronouns
  - While we can implement these systems in the Anglosphere relatively easily, more research and community involvement is needed in other locales
- Gender identity + assigned gender at birth is still a proxy for other information, such as organ inventory
  - It is a better proxy than just “administrative gender” though
  - It is an incremental step toward individualized care with organ inventories, hormonal profiles, genetic screenings, and the like, but tends to avoid some pitfalls of those systems currently, such as cost considerations and invasiveness of procedures

# Conclusions

- Alignment with the minimum option sets provided by the HL7 Gender Harmony Project and the standards laid out in Kronk et al is a beginning step, not the end-all, be-all.
- Always involve local communities in data building continuously, and include mechanisms for feedback and change that are reportable.
- More data doesn't always equal better care. It may even make care more dangerous. Be careful and consider that these “data points” are representations of human lives.







Q&A