



MODELING AND
OPERATIONALIZING GENDER, SEX,
AND SEXUAL ORIENTATION:
RECOMMENDATIONS AND
FUTURE DIRECTIONS

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About Me

- Postdoctoral researcher at the University of Cincinnati School of Medicine.*
- Author of the Gender, Sex, and Sexual Orientation (GSSO) ontology, consisting of over 10,000 terms (available at gssso.info).
- Consultant for HL7's Gender Harmony Project, SNOMED's former Sex and Gender Clinical Project Group, the Homosaurus vocabulary, the Trans Metadata Collective, Queensland Health Gender and Sex Sub Working Group, Canada Health Infoway, and the AMIA Diversity, Equity, and Inclusion Task Force.



Operationalization

- **How is a datum currently ascertained?**
- **How is that datum processed?**
- **How is that datum interpreted by providers?**
- **How is that datum utilized by researchers?**

Operationalization

- **How is a datum currently ascertained?**
 - Is a question asked verbally? By whom?
 - Is a question part of a written form?
 - Is a question recorded from another document, such as a passport?
 - Is a question directly entered into a computer?
- **How is that datum processed?**
- **How is that datum interpreted by providers?**
- **How is that datum utilized by researchers?**

Operationalization

- **How is a datum currently ascertained?**
- **How is that datum processed?**
 - Who enters the data? How have they been trained to enter the data?
 - How does the source get transcribed? Does its datatype get changed?
 - What kind of software and standards are utilized and why?
- **How is that datum interpreted by providers?**
- **How is that datum utilized by researchers?**

Operationalization

- **How is a datum currently ascertained?**
- **How is that datum processed?**
- **How is that datum interpreted by providers?**
 - What alerts and suggestions does the datum trigger?
 - Do all individuals have the ability to see or change the datum?
 - Can providers ignore or circumnavigate the datum to provide accurate care when necessary?
- **How is that datum utilized by researchers?**

Operationalization

- **How is a datum currently ascertained?**
- **How is that datum processed?**
- **How is that datum interpreted by providers?**
- **How is that datum utilized by researchers?**
 - How do researchers interpret the aforementioned processes?
 - How accurate is the datum to some “ground truth”?
 - Can the datum be relied upon when all the above operationalization procedures may be extremely different?

Use Case 1: Reference Ranges

- Oftentimes, outdated medical devices and algorithms use “male” or “female” as binaristic options; even affirming providers are forced to use them.
- How do we know what is correct? How will it affect patients?
- Hormonal therapy status and length, pregnancy status, menarche/menopause status, surgical statuses, and a number of other factors can affect appropriate reference range values.
- Using the wrong reference ranges may cause misdiagnosis, severe injury, or, in extreme cases, death.
- CAIS XY individuals require “male” ranges in some cases and “female” ranges in others.
- “Female” ranges may be necessary in individuals with PCOS to avoid ovarian and/or adrenal tumors.
- Inadequately described troponin I levels in trans man and trans women may lead to misdiagnosis or missed myocardial infarct.

Use Case 2: Exploring or Questioning

- Not all individuals are “out” in all situations.
- In many cases in the U.S., medical reimbursements are tied to employment and medical claims may be visible to individuals who shouldn't be privy to them.
- For those on a guardian's insurance, billing codes using ICD may unnecessarily out individuals or put them at risk.
- Reports and records on individuals may be requested by some governmental agencies and may be used in litigation suits against people; medical records privacy is not protected in all cases.
- Outing of individuals has led to severe medical neglect by providers, suicide, and to a number of other negative health (and life) outcomes.
- How do we make space for exploring or questioning gender and sexuality in care?

Use Case 3: Documentation

- Matching legal documents and insurance documents may be necessary for certain procedure or prescription approvals.
- Patient matching based on demographic factors and documentation can mean the difference between someone having a relative by their side before they pass away, and dying as an unknown person.
- Intersex persons medical records are commonly altered by medical providers, meaning their histories might be near impossible to sort through without thorough documentation.
- Trans people are forced through multi-year long name and gender change processes which oftentimes require medical letters matching documents.

What Should Be Modeled?

- The universes of things we can and should model can be vastly different.
- Consider power in the hands of a provider versus power in the hands of a patient.
- For instance, it does not make sense to say that hormone levels are “female” or “male”, or that a patient has “testosterone” and another does not. Everyone has these hormones and their levels often overlap in expected ways.
- Hormones are already implicitly modeled in prescriptions and drug inventories.
- Organ inventories can be modeled as lists and operationalized, but cannot be binary yes/no or presence/absence options; there needs to be an “something else, please specify” due to considerations of intermediate states which may be more common than expected.

Phrasing a Question

- How a question is phrased can have extreme consequences.
 - Clinics must be assumed to be multilingual.
 - Clinics oftentimes regularly deal with people who cannot read or write for various reasons.
 - Clinics may not provide patients privacy in answering questions or may write down things different than what a patient reported for various reasons.
- Is a perfect question even possible?
 - **No.**
 - And that's okay.
- But providing an appropriate question is necessary to providing appropriate answers.
- Overly verbose questions may seem alluring at first but are difficult to operationalize and oftentimes lead to issues with understanding among patients and providers.

Modeling a Question

- What is the question *really* meant to ask, versus what is understood by the patient and the provider?
- In all cases here, I will provide *starting points*. These are not the “end-all-be-all” and they shouldn’t be considered as such. They should be considered *starting points* with which to engage with local and context-specific information relevant to practice.

“Sex”

- Oftentimes, the dichotomy of “sex” versus “gender” is presented, without consideration of what that necessarily means.
- Terms like “biological sex” and “assigned sex at birth” (ASAB) have gained popularity, but are also nonspecific.
- ASAB becomes *assigned gender at birth* in practice because it has become equated with legal documents (like birth certificates) which are culturally-dependent.
- “Biological sex” is a misnomer because there are a number of biological components which can be considered “sex-linked” but not sex essential.

Sex for Clinical Use (SFCU)

- HL7's Gender Harmony Project decided to solve the "sex" conundrum using a datum called *sex for clinical use*.
- The four values for SFCU will be "male", "female", "specified", and "unknown". These values will not be descriptors of a person, but rather of an order or report, so they may be multivalued depending on context.

What about *assigned gender*?

- HL7's Gender Harmony Project decided to code *assigned gender* (sometimes rendered as *assigned sex*) as a "recorded sex or gender" datum.
- This is because gender assignment happens using a number of different medico-legal processes worldwide.
- Gender might be assigned before birth, at birth, in infancy, in childhood, etc.

A Starting Point for AGAB

- **What is your assigned gender at birth, meaning the gender marker which appears on your original birth certificate? (Select one.)**
 - Female ('F')
 - Male ('M')
 - X
 - Unsure
 - Prefer not to disclose
 - Assigned gender at birth not listed (please specify)
- Depending on location, other markers may be appropriate.
- It is *never* appropriate to use AGAB outside of particular clinical and research contexts. It should NOT be used in governmental, academic (such as scholarship or fellowship information), or employment-based forms in almost all situations.

“Gender”

- It is of note that over 90% of world languages do not have a word for *gender*, meaning that qualifier terms are necessary.
- When we say gender, are we referring to *gender identity*, *gender expression*, or *gender modality*?
- Language around gender has changed rapidly, while standards tend to be more static; how do we balance between the two?
- “Gender expression” is extremely culturally-dependent and has been connected to sexism, homophobia, and transphobia (such as with the “real-life test”).
- “Gender modality” is a newer term and has been little studied in research or clinical practice.
- “Gender identity” is therefore the most useful in practice.

Gender Identity

- An individual's conception of their gender identity may change over time for any number of reasons.
- Individuals may have more than one gender identity simultaneously.
- Gender identity *does not* equal pronouns, honorifics, or other gendered language.
- An individual may present a different apparent gender identity at different times and contexts, and that should be respected.
- Gender identity may be considered in place of “administrative gender” for situations like appropriate bed placement.
- When we ask gender identity, it is really asking *current self-identified gender identity* as a proxy for gender identity, since we can't read people's minds. Just using “gender identity” is more readable and understandable though.

A Starting Point for Gender Identity

- **What is your gender identity? (Choose all that apply.)**
 - Female
 - Male
 - Nonbinary
 - Questioning or exploring
 - Prefer not to disclose
 - Gender identity not listed (please specify)
- Depending on if age groups are important or if a clinic is age group specific, “female” could be replaced with “woman” or “girl” and “male” could be replaced with “man” or “boy”.
- Culturally-specific considerations may be location or context dependent. “Two-Spirit”, for instance, has a different meaning among Indigenous Australians and Torres Islanders than among Native American and First Nations peoples.

Example Extensions to Consider in the United States and Canada

- Two-Spirit (Native American and First Nations)
- Fa'afafine and Fa'afatama (Samoaan diaspora)
- Māhū (Hawaiians)
- Palao'ana (Chamorro people)

“Sexual Orientation”

- Sexuality is likewise complicated. Social constructionism of sexual orientation is somewhat more murky than constructions of sex and gender.
- When asking for sexual orientation, we are really asking for *sexual orientation identity* (sometimes shortened to “sexual identity”). However, this is often confused with gender identity, especially when translated into non-English languages.
- Personally, I consider sexual orientation to be one’s tendencies of sexual attraction, related to gender and degree of attraction, when considered as a whole.
- Sexual orientation identity is one’s relationship between that tendency and a socially constructed label.
- This is a practical definition based on social norms, not a descriptor of some underlying biological reality.

A Starting Point for Sexual Orientation

- **What is your sexual orientation? (Choose one.)**

- Heterosexual (Straight; Not gay or lesbian)
- Gay or Lesbian
- Bisexual or Pansexual
- Asexual
- Questioning or Exploring
- A sexual orientation not listed (please specify)

- Note that allowing individuals to choose more than one option may be appropriate in some situations.
- Anecdotally, many older heterosexual persons do not understand the terms “straight” or “heterosexual”, hence the addition of “not gay or lesbian”).
- Grouping of gay and lesbian together may be inappropriate in some situations (same with bisexual and pansexual).
- Asexuality is often considered as a spectrum and changing to “Asexual spectrum” may be more appropriate.

Clinical Practice Implications

- SFCU allows for more individualized care for trans, intersex, and gender-diverse patients without necessarily impacting care for cisgender non-intersex patients (wherein the same SFCU could be loaded every time).
- The HL7 Gender Harmony Project, like many clinical standards, is designed with clinical practice and safety, as well as with patient privacy, first and with research implications second.
- Multi-value systems can make insurance claims and patient matching systems less complicated, and we can move these systems slowly away from actual care.
- Gender histories can be recorded for individuals who are genderfluid or exploring gender identity, which can be helpful for affirming clinicians.

Research Implications

- Effectively, we have suggested a two-step for measuring gender modality, instead of a one-step.
- This has shown increased ascertainment of both cis and trans status in clinical and non-clinical settings.
- Trans, intersex, and gender-diverse communities are not monoliths. There may be some push back on particular phrasing in some situations.
- AGAB can still easily be coded as a recorded sex or gender datum, making the two-step fundamentally the best way to foster study reproducibility.
- There is a fundamental difference in making categorization of people easier for researchers, and provided safe and effective care for patients. This means that researchers will likely have to continue using multiple approach models for trans, intersex, and gender-diverse populations.

Guiding Principles and Rules of Thumb

- Be careful when considering “bad actors”. It has been my experience that a number of transphobic hate groups have attempted to position themselves as “experts” in standards communities.
- Design your system for the most vulnerable people in the worst-case situations. Always.
- Avoid terminology which may be exploited and hypothesize how every term or concept considered could be abused.
- Contact local, national, and/or international trans, intersex, and gender-diverse organizations.
- Compensate trans, intersex, and gender-diverse people for their work. Don't make it an afterthought.
- Build with operationalization, patient safety, and clinical practice first, and with other considerations second.
- Consider that “fringe” cases might not be as rare as you might think.
- Not everywhere does things that same way, *and sometimes that's okay.*

Conclusions

- Non-English language pronouns and all language honorific and gendered language are still in need of building out.
- Most individuals involved in standards work are white cisgender heterosexual men, and quite a large number are retirees. This heavily effects ideological stances which persevere for far too long, such as “sodomy” being in SNOMED CT.
- HL7's Gender Harmony Project is a beginning to phasing out systems based on inadequate modeling of “sex”. However, it still has to accommodate all systems. Some local or national terminologies may have an easier time phasing out sex-related algorithms and devices.
- It's a tough process and it takes a lot of work, but it will save lives.



Questions?