Beyond the Binary
Gender Inclusive Genetics Services

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she/they she/her

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Speakers

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Disclosures

Neither of us have any conflicts of interest to disclose.

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Establishing space

- **Be open**: You are here to learn and engage with new ideas.
- **Be respectful**: When asking questions, be mindful of your language - we have gender-diverse peers in this webinar.
- **Self-correct**: If you used the wrong name, pronoun, or terminology, apologize, correct yourself, and move on.
- **Assume good intentions**: While we are all different people with different experiences, beliefs, and customs, assume we are all coming together with good intentions to learn.

Transphobia, homophobia, and racism will not be tolerated

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The Legacy of Trans Resistance

- Dewey’s sit-ins
- Compton’s Cafeteria Riots
- Stonewall Riots
- Cooper Do-nuts Riot
Pride exists because of a Black, bisexual, trans woman who was a sex worker that resisted the police and started a riot.

Marsha P. Johnson was murdered & Sylvia Rivera died homeless

23 trans people have been murdered in 2021 in the US; on track to be the deadliest year for trans folks

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We live in a white supremacist, capitalist patriarchy. European colonialism imposed the binary gender system across the world through genocide and conquest.

**Gender liberation goes beyond equality, but requires the fundamental transformation of society.**

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https://roadtoliberation.org/points-of-unity-on-gender-liberation/
Institutions that interfaces with other institutions (governmental, research)

Pathologization of differences (sexual orientation, sex characteristics, etc.)

Strict categorization for standardization of care

Looks toward past for evidence

Institutional discrimination and violence impacts trust

Freedom of Self-Determination

Celebration of liminality, or existing outside categories

Queerness largely erased from recorded history

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LACK OF ACCEPTANCE
- LGBT patients higher rates of discrimination in healthcare
- 1/5 transgender patients turned away by provider

LACK OF ACCESS
- Decreased access to health insurance
- Limited insurance coverage for gender affirmation
- Insurance coverage dependent on sex

LACK OF EDUCATION
- 33-50% of trans/non-binary individuals report having to educate providers about transgender health

Healthcare Disparities

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“Often no, [I do not disclose my gender to colleagues], because it means I have to do a lot of educating first which is tiring. Not all work spaces are even safe/welcoming to non-hetero people, let alone non-cis people”

- Anonymous gender diverse GC
Why does this matter for healthcare providers?

- We see LGBTQIA+ patients
  - 6% in USA identify as lesbian, gay, or bisexual
  - 1 in 6 Gen Z considers themselves LGBT
  - ~1% identify as transgender
  - ~2% born with intersex traits
- We understand the importance of culturally sensitive language
- Genetic counselors were shown to have implicit preferences for heterosexual over homosexual people (Nathan, 2019)
- Only 24% of GCs reported transgender health training (Berro, 2019)
“Empathy does not guarantee or assure that someone is going to care enough to do something, especially if they need a framework or word to do it.”

- Ericka Hart, M.Ed.
Terminology

Slides are property of the presenter. Do not duplicate without permission.
**Sex** - sex assigned at birth, based on assessment of external genitalia, chromosomes, and/or gonads

**Gender identity** - a personal awareness of being a man, woman, non-binary person, and/or another gender

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Beyond XX and XY: The Extraordinary Complexity of Sex Determination
Gender diverse

An umbrella term that is used to describe gender identities that demonstrate a diversity of expression beyond the binary framework. For many gender diverse people, the concept of binary gender – having to choose to express yourself as male or female – is constraining.
Transgender/Trans

Both an umbrella term including many gender identities and a specific gender identity that describes those with a gender identity that's different from the sex assigned at birth (male, female, or intersex).
Nonbinary/Genderqueer

Gender identity and umbrella term for gender identities that can’t be exclusively categorized as male or female.
Cisnormativity

The assumption that a person identifies with the sex or gender they were assigned at birth, or that having a cisgender gender identity is the norm.
Pronouns

The pronoun or set of pronouns that a person identifies with
E.g. She/her, he/him, ze/zir, they/them, xe/xem, ze/hir, etc or a combination like she/they, he/they

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Sexual orientation

Sexual attraction, not directly related to gender identity

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Gender affirmation therapies

Medical interventions that gender diverse people **MAY** choose to express gender identity.

- Hormone therapy
- Surgery
- Facial hair removal
- Modification of speech and communication

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Pedigrees

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Transgender/non-binary individuals

NSGC recommendations (currently being updated)

NCCN recommendations

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Trans-approved recommendation

Gender identity = the symbol
AFAB or AMAB indicated in the upper left corner

Barnes, 2019
Inclusive services

- Preface importance of differentiating sex assigned at birth and gender
  - “I will use shapes to represent you and your family members. It may be important for my evaluation to know both the gender identity and the sex assigned at birth.”

- Address privacy and confidentiality concerns
  - Who has access to the pedigree?
  - Do they want other HCPs to know they’re trans?

Barnes, 2019
Specialty-based considerations
“It is not uncommon for providers to state ‘I treat all my patients the same.’ This mentality underscores the need for training, because the goal of quality health care is for equity and not equality. The heteronormative assumptions of providers are the very reason why LGBTQI individuals do not want to be treated ‘the same.’”

- Quinn, 2014
Cancer

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Concern over hormone impact on cancer risks
- Implications of estrogen therapy on breast cancer risk
- Implications of testosterone on ovarian and endometrial cancer
- Minors starting hormone therapy

Pathogenic variant for insurance coverage
- Risk-reducing bilateral mastectomy covered by insurance with a BRCA mutation

Referrals
Gender affirming surgical considerations
- Top surgery vs risk-reducing bilateral mastectomy

Zayhowski, 2019; Berro, 2019
Hormone implications

Lack of consistent guidelines or clear research on the impact of hormone use to cancer risk

Fear by providers to give patients hormones if there is a genetic cancer disposition in family history

Transgender individuals often have fear of hormones being taken away or not prescribed (Sevelius, 2013)
Language

Don’t use:
- Female reproductive cancers
  + Instead, name the specific organs
- Male and female hormones
  + Instead, name the specific hormones
Guidelines for screening

- UCSF Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People
  (http://transhealth.ucsf.edu/protocols)
Prenatal
“Another microaggression that comes to mind is how gendered... the prenatal setting [is]. It's SO Mom + Dad + baby-boy/baby-girl. All the forms are so cis-heteronormative. It feels like an entire world in which I do not belong.”

- Anonymous gender diverse GC
Areas for improvement

- Forms
  - Flipbooks
  - Lab forms
  - Intake
- Language
  - AMA
  - Mom and Dad (vs parent)
  - Sperm and eggs
- Waiting Rooms
  - Gendered spaces
- Provider discrimination
  - Over-curiosity

Ruderman, 2020
Language

Do use:

+ **mother and father** → “We have two copies of every gene: one from the egg and one from the sperm”
+ **gender of the baby** → **Sex of baby**
+ **husband or wife** → **Partner**
+ “Is this your wife?” → “What is your relationship to each other?”
+ **Donor**
Prenatal sex chromosome screening

- Distinguish sex and gender
- Avoid “boy” and “girl”
- Remind patients that NIPS is a screen for sex chromosomes, not gender

“X and Y chromosomes are called sex chromosomes because they influence things like genitals, reproduction, and puberty. For example, having XX chromosomes is often associated with features of female sex, and having XY chromosomes is often associated with features of male sex.”

“This screening can give us information about one factor that influences sex, sex chromosomes, but there are other factors that also influence someone’s sex, like hormones, the environment, and other genes. For example, pictures from the ultrasound can suggest a different sex than the results of this screen.”
## Gender affirmation therapies and pregnancy

<table>
<thead>
<tr>
<th>Testosterone</th>
<th>Chest (“top”) surgery</th>
<th>Genital (“bottom”) surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not contraception, though thought to decrease conception rate</td>
<td>Chest feeding may be possible after certain forms of chest surgery</td>
<td>Metoidioplasty, scrotoplasty, or phalloplasty do not impair future reproductive options, but necessitate c-section</td>
</tr>
<tr>
<td>Some evidence suggests teratogen*</td>
<td>Likely not possible to tell prior to attempting to chest feed whether it is possible</td>
<td>Vaginectomy combined with TAH and/or BSO eliminates chance for future pregnancy</td>
</tr>
<tr>
<td>Effects while lactating are unknown - no clear evidence of harm</td>
<td>Encourage patient to discuss with surgeon</td>
<td></td>
</tr>
</tbody>
</table>

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*Hoffkling, 2017

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Inclusivity in clinic

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Balancing liability with respectful patient care

- Bring up risk in neutral way (Contract/Consent)
  - Is this something that is relevant to you?
  - Is this something you want to talk about?
  - Do you want to hear more about this?
- If patient does not, document in the note the recommendation without using gendered language
  - Discussed risk for cancer
  - Discussed risk for pregnancy
  - Discussed risk for hormones

Prioritize rapport and respect over forced information
Recommendations for clinical encounters

- Reflect language patients use to describe body parts
- Educate yourself, don’t rely on your patient
- Be open to patients’ expertise and learning when they want to share
- Explain why sensitive questions are relevant
- Continue to maintain good medical care and judgment

Hoffkling, 2017
Test requisition forms

- Many not be inclusive of transgender or non-binary people
  - Options for sex/gender limited to sex assigned at birth
  - Can be triggering for patients if report not under correct gender
  - Can queue laboratory error if inputted gender is not assigned sex at birth
- Insurance may be under a dead or different name

Advocate to your genetic testing labs that forms need to be re-structured to be inclusive!

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Asking about name and pronouns

Do:
+ “Do you have any medical records under a different name?”
+ “Is that the name you go by?”

Do:
+ Clinic form with pronoun question is best practice
+ Ask *ALL* patients what pronouns the person uses at the beginning on sessions

Lyninger, 2019

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“It’s okay to make mistakes! We can tell the difference between someone who tries and makes a mistake vs. someone who doesn’t care.”

- Anonymous gender diverse GC
Environment

**Bathrooms**
- Gender neutral/inclusive bathrooms

**Cultural Humility**
- Each patient is an individual, with their own needs and desire for the appointment
- If you mess up, apologize and move on
- Prioritize rapport and respect over forced information

**Signs**
- Indications that the office is affirming
- Pronouns on ID/Zoom/business card
- Trans flag pin

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Peer inclusivity
Cool!
You're my first trans friend.

So when are you gonna REALLY transition?
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Microaggressions reported by gender diverse GCs

- Putting onus on LGBTQIA+ students and peers to teach
- Asking inappropriate questions
- Assuming gender/sexuality
- Overemphasizing/ “you’re so brave!”
- Out-ing without permission
- Apologizing profusely when misgendering
- “I’m sure they meant well” “They were coming from the right place”
- Defensiveness when wrong
- Dress-code language (often gendered, not allowing for gender diverse expression under the guise of “professionalism”)
“[I want to tell people] not to assume our gender or our sexuality, especially if we’re POC and don’t fit into the stereotype of what LGBTQ+ people ‘look like’ (which is often based on the white LGBTQ+ community).”

- Anonymous gender diverse GC
“It should not always be my responsibility as a queer person to advocate for GLBTQ+ issues in our clinic: any provider can and should. The times when other providers have spoken up about GLBTQ+ issues really mean a lot to me.”

- Anonymous gender diverse GC
“Low-hanging fruit”

- During presentations:
  - DEI issues adjacent to your topic
  - Case examples and pictures that illustrate range of identities
  - Affirming language

- During rotations:
  - Asking/sharing pronouns
  - Offer other people that student can talk to if they feel uncomfortable discussing concerns about supervisor due to power differential
  - Consider what are appropriate personal questions to ask students
  - Have a plan for dealing with microaggressions and aggressions

Ask yourself - how does my lens influence how I approach the situation? What are some things I could be missing?

Stanford DEI AOC

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Questions?