

Sex, Sexual Orientation, and Gender Identity (SSOGI) Data Collection

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Lauren B. Beach, JD, PhD (they/them)

Assistant Professor

Department of Medical Social Sciences

Northwestern Feinberg School of Medicine

Director, ADVOCAGE SGM Program

Institute for Sexual and Gender Minority Health and Wellbeing

Northwestern



Institute for Sexual
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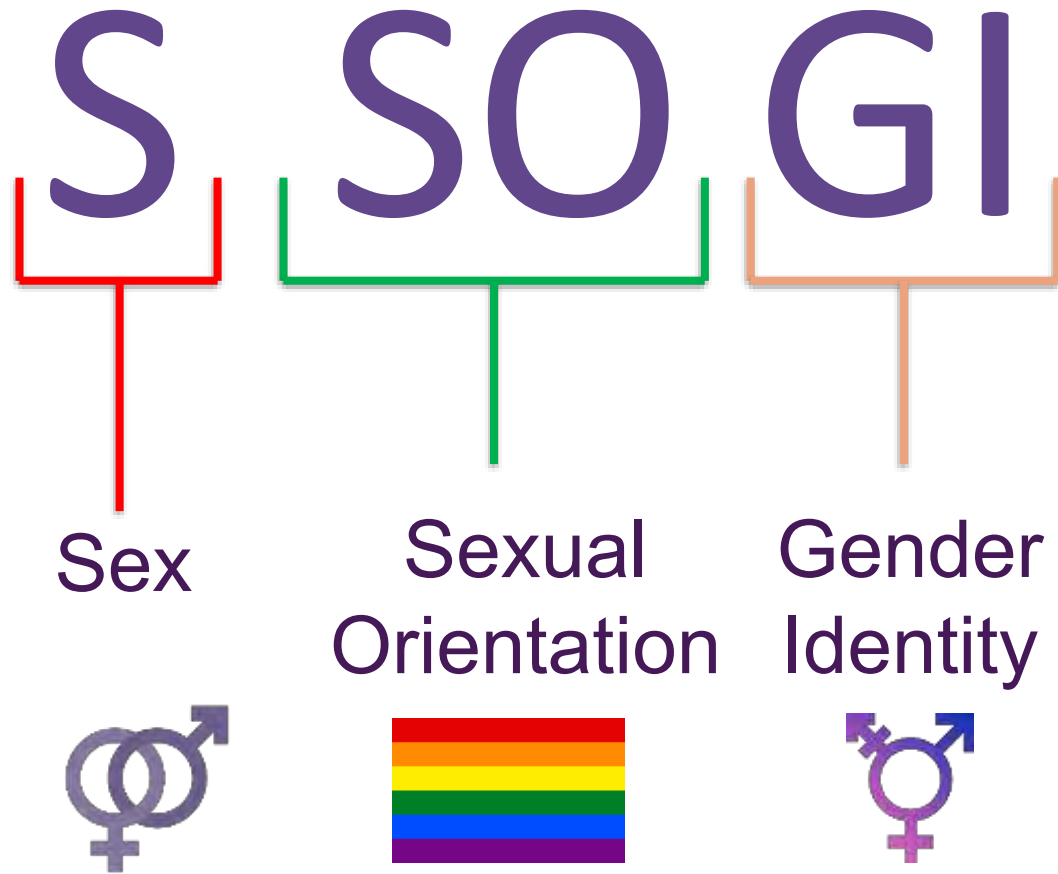


Disclosures

- None

Learning Objectives

- Learners will be able to list at least 3 important reasons why it is important to collect SSOGI data
- Learners will be able to name at least 3 best practices in the collection of SSOGI data in healthcare
- Learners will be able to identify at least 1 way they can help their clinic facilitate SSOGI data collection



LGBT By The Numbers

- 7.6% of adults identify as lesbian, gay, bisexual, or transgender
- 57.3% of LGBT adults identify as bisexual
- 22.3% of Gen Z individuals identify as LGBT

LGBTQ+ Identity Among U.S. Adults and LGBTQ+ Adults, 2023

Which of the following do you consider yourself to be? You can select as many as apply. Straight or heterosexual; Lesbian; Gay; Bisexual; Transgender

	U.S. adults	LGBTQ+ adults
	%	%
Lesbian	1.2	15.1
Gay	1.4	18.1
Bisexual	4.4	57.3
Transgender	0.9	11.8
Pansexual (vol.)	0.1	1.7
Asexual (vol.)	0.1	1.3
Queer (vol.)	<0.1	0.1
Other LGBTQ+ (vol.)	0.1	1.1

Sum of categories may exceed 100% or the total because respondents can choose multiple identities.
(vol.) = Volunteered response
Based on aggregated data from 2023 Gallup telephone polls.

[Get the data](#) • [Download image](#)

GALLUP

LGBTQ People Experience Health Disparities that Increase Cancer Risk

Family Acceptance



Mental Health



Homelessness



HIV



Healthcare Access



Substance Use



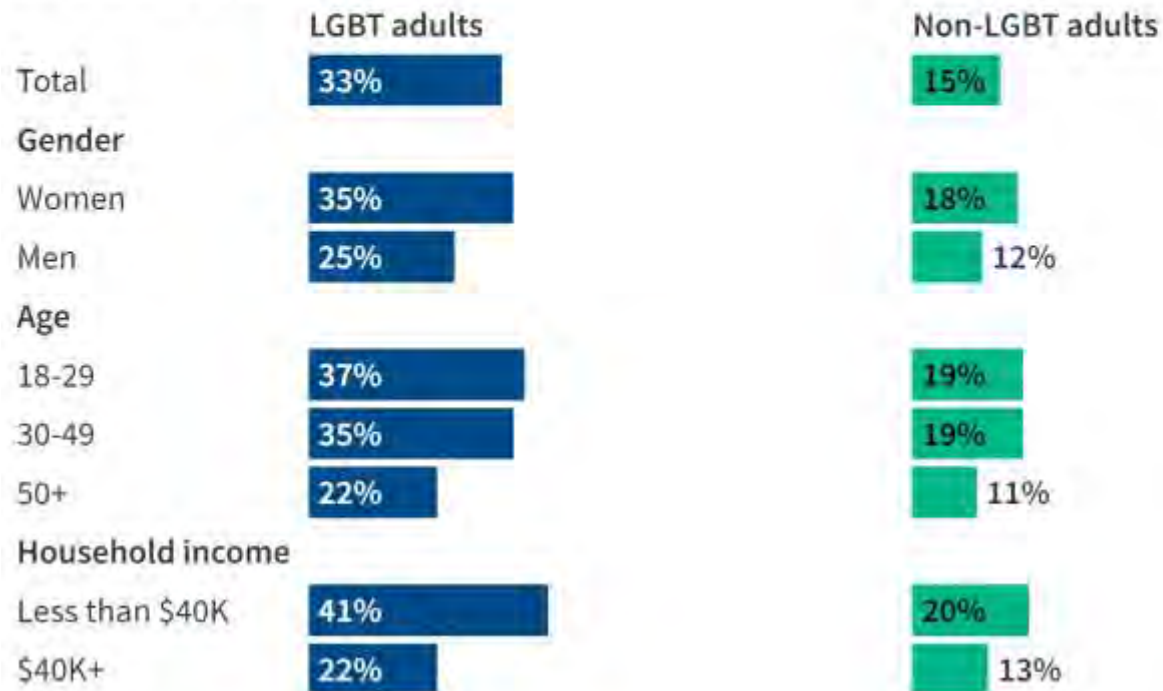
Bullying/
Victimization



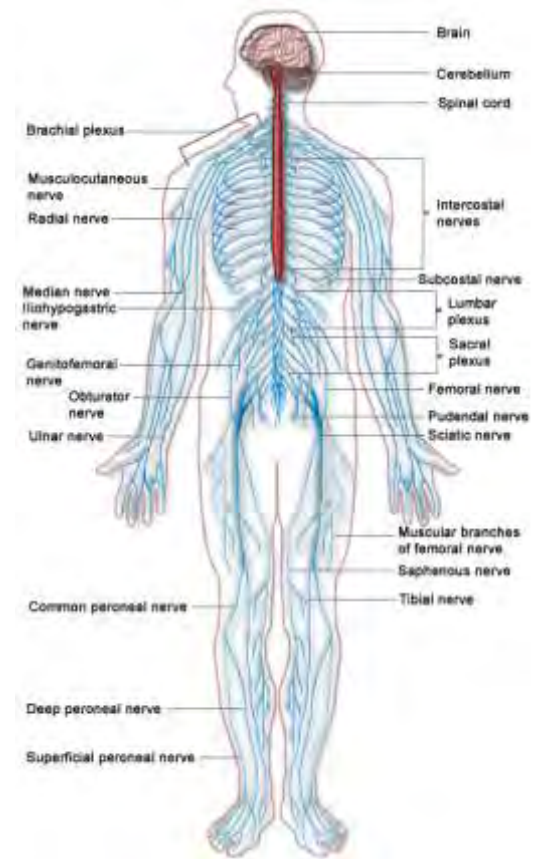
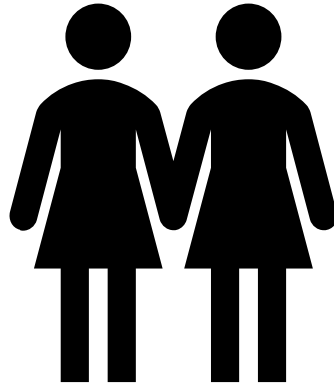
LGBT Adults Report High Levels of Healthcare Discrimination

One-Third of LGBT Adults Report Experiencing Unfair, Disrespectful Treatment by a Health Care Provider, Including Four in Ten Lower-Income LGBT Adults

Percent who say that a doctor or other health care provider treated them unfairly or with disrespect in the past three years for any reason:



SSOGI Data Collection is Part of High Quality Patient Care



Patient Case

Jessica is a 32-year-old transgender woman who presents to oncology to establish care after being diagnosed with prostate cancer at an outside healthcare system. Jessica uses she/her pronouns, is taking gender-affirming hormones, and received gender-affirming surgery. After presenting her information to the front desk staff, she is told, "You can take a seat in the waiting room and we will be right with you, Mark." After being roomed, Jessica overhears the MA tells her physician, "He is in room 3." When the physician comes to see her, he notices that she is taking spironolactone. He asks her "Do you have male or female anatomy?" Jessica appears frustrated and does not return to the clinic.

What went wrong?

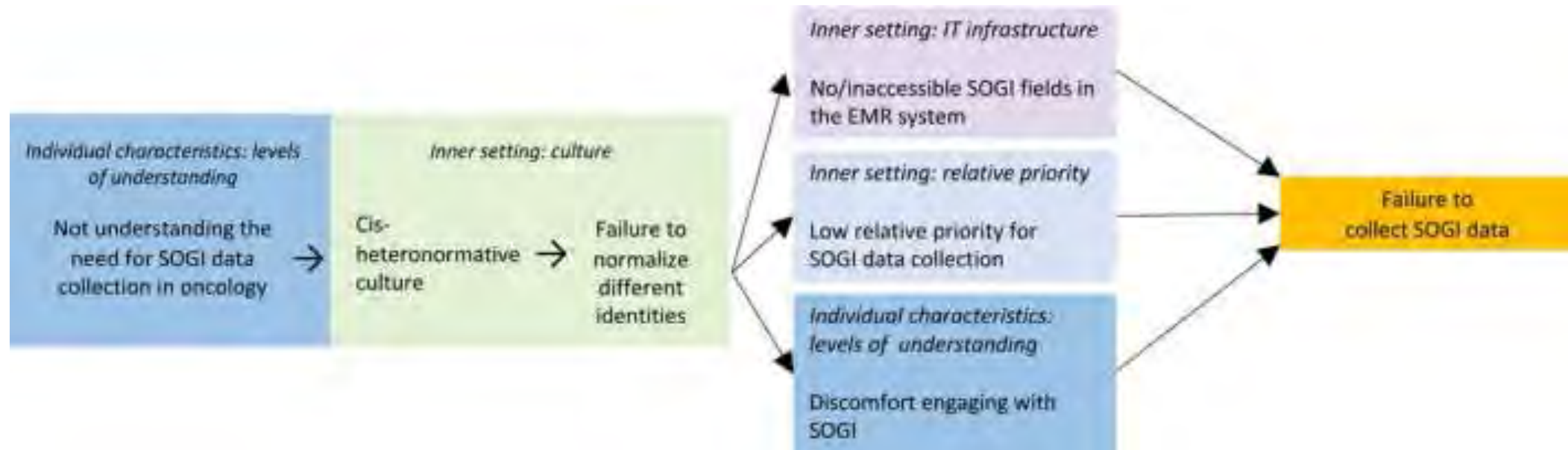
How could this be prevented in the future?

Summary: Why does collecting this information matter?

- Increased clinical workflow efficiency
 - Ensuring patients get the right form at the right time
- Medical errors
 - Improved capacity to determine correct necessary screening
- Reduced patient dissatisfaction
 - Increased visibility of patients preferred name and pronouns
- Facilitates history and physical exam taking
 - Reduced confusion

Barriers and Facilitators to SSOGI Data Collection in Oncology

- Mullins et al., 2023, *Barriers, facilitators, and recommendations for sexual orientation and gender identity data collection in community oncology practices*
- Evaluated multilevel barriers and facilitators for SOGI data collection at NCI Community Oncology Research Program practices
- Model of oncology clinician and staff reported SOGI data collection barriers and facilitators:



- Suggested solutions: normalizing asking SOGI questions, giving patients privacy to complete SOGI, and clarifying clinical relevance

National Context: Facilitators of SSOGI Data Collection in Oncology

- In a survey of ASCO members, prevalence of SSOGI data collection was **40%** for SO and **46%** for GI
- Most respondents felt knowing both SO (77%) and GI (85%) was important for quality cancer care
- Collection of SO and GI significantly associated in separate models with...
 - **leadership support** (ORs = 8.01 and 6.02, respectively)
 - **having resources for SOGI data collection** (ORs = 10.6 and 18.7, respectively)
 - **belief that knowing patient SO and GI is important** (ORs = 4.28 and 2.76, respectively)
- Policy mandates, implementation science, and clinical reimbursement are strategies to advance meaningful data collection and use in clinical practice

SSOGI Data Collection Best Practices

We know how to address common concerns about collecting SSOGI data



Concern: I don't want to offend people



Concern: This private information doesn't seem necessary or relevant to collect



Concern: I have limited time and collecting this information is not a priority



Concern: I need more training

Do Ask, Do Tell

- Existing research shows high patient acceptability of SSOGI questionnaires
 - Focus groups and patient interviews can be used to examine this within the context of NM

High Patient Acceptance

All patients (across age, race, ethnicity) in multiple-outpatient settings report **high levels of acceptance and satisfaction with collection of personal SOGI data.**

Increased Patient Comfort

SGM patients to emergency rooms report **greater comfort and improved communication when SOGI was collected** via nonverbal self-report. Non-SGM have no preference.

Low Refusal Rates

Assessment of SOGI has been added to multiple national studies and **missing/refused to answer responses to SOGI questions in these datasets are typically less than 5%** (lower than missing/refused to answer income)

Practice Point: Modeling Inclusive Language

- Hi, my name is (care provider role title) + (name), I use they and she pronouns. How are you doing today?
- What name and pronouns would you like me to use to refer to you?
- I'm going to ask you a few standard questions we are asking all our patients to improve the care that we offer.
 - Instead of, "Do you identify as LGBT?", use "How do you identify?"
 - Instead of, "Do you have sex with men, women, or both?", use "What are the genders of your partners?"

Sticky Situations

- If you realize you made a mistake, apologize and move on.
 - "Sorry for using the incorrect pronouns. I will do better"
 - "I apologize. What pronouns do you use?"
- If someone is upset by the question, explain that it is part of routine care.
 - "These are questions that we ask all patients as a part of routine care"

How to Access the SSOGI Smart Form in Epic

- Left click on the patient's gender, age, or date of birth from the Storyboard to open the SSOGI Smart Form
- An information icon appears next to the patient's gender or sex to let users know there is additional information about the patient's sex or gender that pertains to their care.
- Hovering over the demographic line on the storyboard will display a popup with more demographic information.

Analyticsnine Dubupgrade
46 y.o., 2/13/1977
MRN: 222011500533
Language: English
Bed: NMH FEINBERG 12 E-1209-01
Cur Location: NMIC 2 Imaging
Code: Not on file (No AD Docs)
Pre-Arrest Interventions: Not on File

Sexual Orientation and Gender Identity SmartForm

Information: The patient that anything entered here will be visible to anyone with access to this information.

Sexuality

Patient's sexual orientation: Lesbian or Gay Straight

Legal Information

Legal first name: Analyticsnine
Legal last name: Dubupgrade
Legal sex: Female Male Unknown X

Gender Identity

Autofill with default responses for: Cisgender female Cisgender male

Patient's gender identity: Female Male Other Choose none Non-binary

Patient's sex assigned at birth: Female Male Uncertain X

Pronoun: He/Him She/Her He/Him/They/Them She/Her/They/Them

Using the SSOGI Smart Form to Document and Update SSOGI Information

- Edit SSOGI information in a clinical session with this comprehensive Smart Form
- When to collect: during clinical intake, social history, sexual history, pre-procedure appointments

Sexual Orientation and Gender Identity SmartForm ?

Inform the patient that anything entered here will be visible to anyone with access to this legal medical record.

Sexuality

Patient's sexual orientation:

Legal Information

Legal first name:

Legal last name:

Legal sex:

Gender Identity

Autofill with default responses for:

Patient's gender identity:

<input type="button" value="Female"/>	<input type="button" value="Male"/>	<input checked="" type="button" value="Transgender Female"/>	<input type="button" value="Transgender Male"/>
<input type="button" value="Other"/>	<input type="button" value="Choose not to disclose"/>	<input type="button" value="Prefer to discuss with my provider"/>	<input type="button" value="Neither exclusively male nor female"/>
<input type="button" value="Non-binary"/>			

Patient's sex assigned at birth:

<input type="button" value="Female"/>	<input checked="" type="button" value="Male"/>	<input type="button" value="Unknown"/>	<input type="button" value="Not recorded on birth certificate"/>	<input type="button" value="Choose not to disclose"/>
<input type="button" value="Uncertain"/>				

Pronoun:

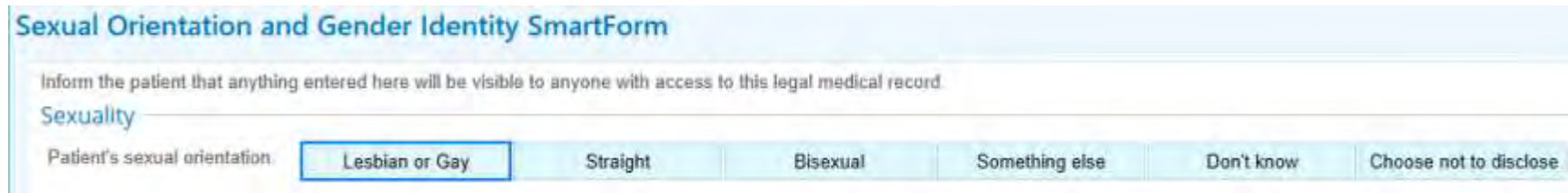
<input type="button" value="He/Him"/>	<input checked="" type="button" value="She/Her"/>	<input type="button" value="They/Them"/>	<input type="button" value="Ze/Zir"/>
<input type="button" value="He/Him/They/Them"/>	<input type="button" value="She/Her/They/Them"/>	<input type="button" value="Other"/>	<input type="button" value="Prefer to discuss with my provider"/>
<input type="button" value="Decline to answer"/>			

Affirmation steps patient has taken, if any:

<input type="button" value="presentation aligned with gender identity"/>	<input type="button" value="preferred name aligned with gender identity"/>	<input type="button" value="legal name aligned with gender identity"/>
<input type="button" value="legal sex aligned with gender identity"/>	<input type="button" value="medical or surgical interventions"/>	

Documenting Sexual Orientation in the Smart Form

- Sexuality

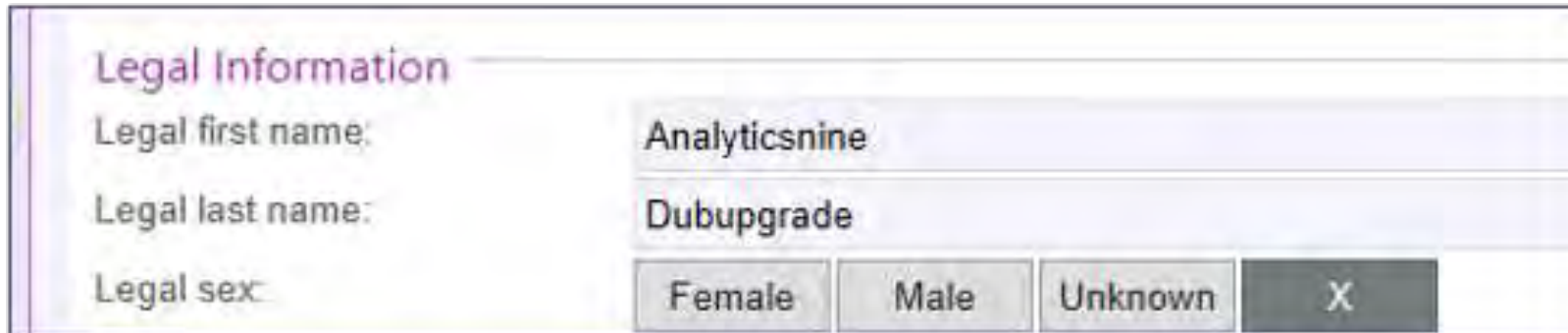


The screenshot shows a web-based form titled "Sexual Orientation and Gender Identity SmartForm". Below the title is a disclaimer: "Inform the patient that anything entered here will be visible to anyone with access to this legal medical record." The form has a section labeled "Sexuality" with the text "Patient's sexual orientation:" followed by six buttons: "Lesbian or Gay", "Straight", "Bisexual", "Something else", "Don't know", and "Choose not to disclose". The "Lesbian or Gay" button is currently selected and highlighted with a blue border.

- Can select all that apply
- "We've begun asking patients about their sex, sexual orientation, and gender identity so we can provide the best care to everybody. Can you tell me how you identify?"
- "Do you consider yourself straight/heterosexual, gay/lesbian/homosexual, bisexual, or something else? If you're not sure, I can explain what these terms mean, and you can also say 'I don't know.'"
- "Is it OK if I put that down in your medical record?"

Documenting Legal Sex in the Smart Form

- Legal Sex
 - The sex (male, female, or X) recorded on an individual's government identification documents
 - Can select one option
 - "What is your legal sex, or the sex listed on your driver's license or passport?"



The screenshot shows a 'Legal Information' section of a form. It contains three input fields: 'Legal first name' with the value 'Analyticsnine', 'Legal last name' with the value 'Dubupgrade', and 'Legal sex' with a radio button selection for 'X'. The 'X' option is highlighted in a dark grey box, indicating it is the selected choice. The other options, 'Female' and 'Male', are in light grey boxes. The 'Unknown' option is also visible but not selected.

Legal first name:	Analyticsnine
Legal last name:	Dubupgrade
Legal sex:	<input type="radio"/> Female <input type="radio"/> Male <input checked="" type="radio"/> Unknown <input checked="" type="radio"/> X

Documenting Sex at Birth and Gender Identity in the Smart Form

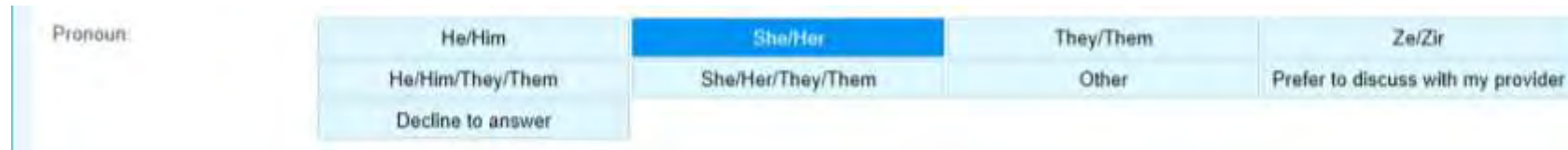
- Gender Identity
 - Can select all that apply
 - "Do you consider yourself female, male, nonbinary, transgender, or something else?"
- Sex Assigned at Birth
 - Can select one option
 - "Were you assigned [female] sex when you were born? I ask this because some people have a gender identity that is different than what is traditionally associated with the sex that they were assigned when they were born."

The screenshot shows a 'Gender Identity' section in a smart form. It includes two tabs: 'Cisgender female' and 'Cisgender male'. Below the tabs are two rows of options. The first row is for 'Patient's gender identity' and the second row is for 'Patient's sex assigned at birth'. The 'Transgender Female' option in the first row and the 'Male' option in the second row are highlighted in blue.

	Cisgender female	Cisgender male				
Autofill with default responses for:						
Patient's gender identity:	Female	Male	Transgender Female	Transgender Male		
	Other	Choose not to disclose	Prefer to discuss with my provider	Neither exclusively male nor female		
	Non-binary					
Patient's sex assigned at birth:	Female	Male	Unknown	Not recorded on birth certificate	Choose not to disclose	
	Uncertain					

Documenting Personal Pronouns in the Smart Form

- Pronouns



The image shows a screenshot of a smart form for selecting pronouns. On the left, there is a label "Pronoun:" followed by a text input field. To the right of the input field is a grid of buttons for selection. The grid has four columns and three rows. The first column contains "He/Him", "He/Him/They/Them", and "Decline to answer". The second column contains "She/Her" (highlighted in blue), "She/Her/They/Them", and "Decline to answer". The third column contains "They/Them" and "Other". The fourth column contains "Ze/Zir" and "Prefer to discuss with my provider".

He/Him	She/Her	They/Them	Ze/Zir
He/Him/They/Them	She/Her/They/Them	Other	Prefer to discuss with my provider
Decline to answer			

- "Which pronouns do you use?"
- "My name is [Dr. Jordan] and I use [she/her] pronouns. May I ask which personal pronouns you use?"
- "We ask this information of everybody to make sure we get it right."

Document Organ Inventory in the Smart Form

- Helpful for clinical decision support tools
- Can add with the “+” sign or remove with the “-” sign all that apply
- "I want to make sure you get the preventive health screening you need, a lot of which relates to anatomy and organs--like screening for breast or prostate cancer. Could we review this?"
- "You selected that your sex assigned at birth was _____. Does that mean you were born with [X, Y, Z] to your knowledge?"
- "Some people have surgery to either remove unwanted organs, like a uterus, or create desired anatomy like a penis, vagina, or breasts. Have you had any surgeries to remove or create [X, Y, Z]?"
- "I know this is personal and specific, but having this information in your medical record helps us ensure you are getting access to the right care."

The screenshot displays the 'Organ Inventory' section of a smart form, organized into four columns. Each column has a title and a list of organs with expandable (+) and collapsible (-) buttons.

Organs the patient currently has:	Organs present at birth or expected at birth to develop:
+ breasts -	+ breasts -
+ cervix -	+ cervix -
+ ovaries -	+ ovaries -
+ uterus -	+ uterus -
+ vagina -	+ vagina -
+ penis -	+ penis -
+ prostate -	+ prostate -
+ testes -	+ testes -

Organs surgically enhanced or constructed:	Organs hormonally enhanced or developed:
+ breasts -	+ breasts -
+ vagina -	
+ penis -	

If Patients are Reluctant to Disclose SSOGI Information

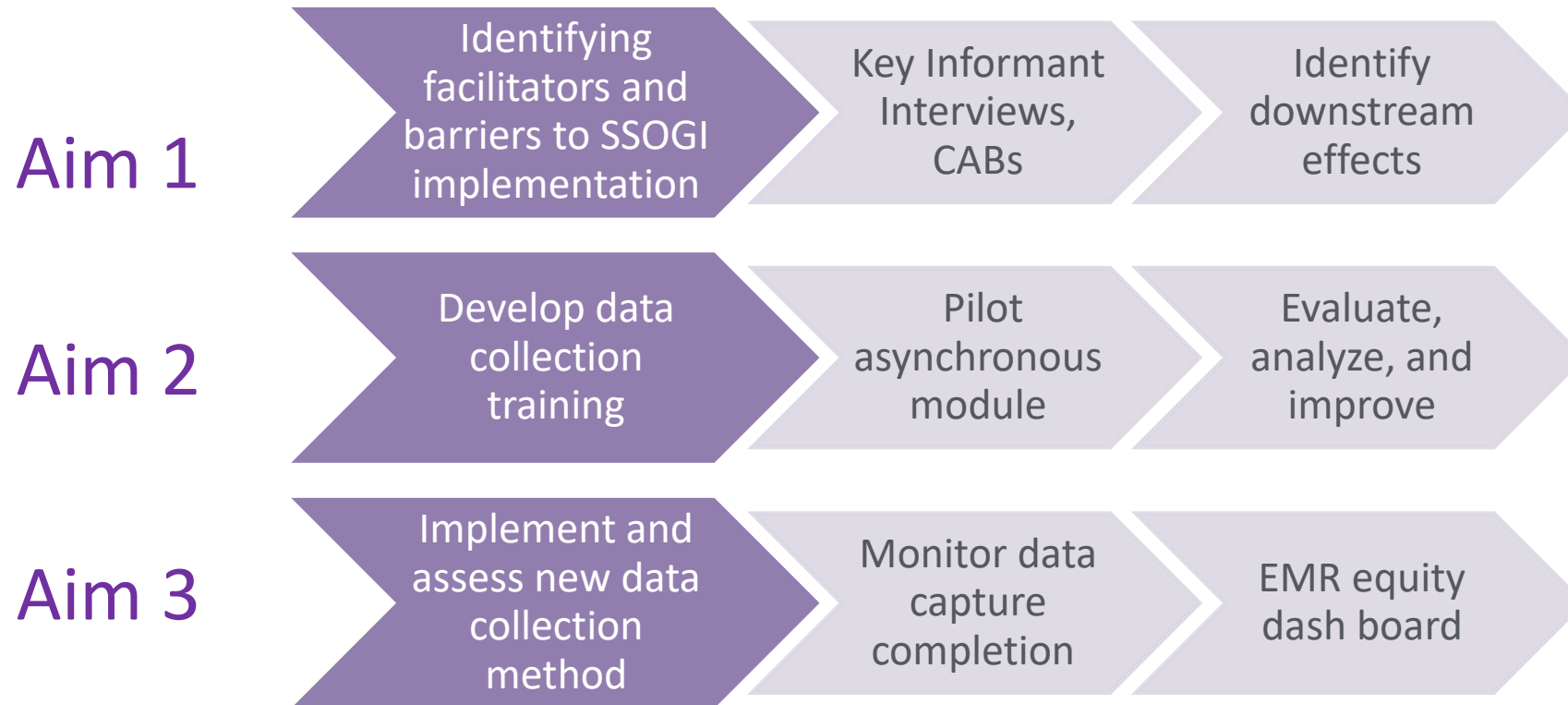
- If a patient is reluctant to provide information, we can reassure them by describing how this information is relevant to their clinical care, that this information will be confidential, or can also record their response as choose not to disclose.
 - "We collect this information because want to make sure that we are able to identify and address all of our patients' needs. It's part of ensuring that everyone receives the highest quality care."
 - "If confidentiality is a concern, I can assure you that this information will be kept private and only relevant health center staff and persons you allow access will be able to see it."
 - "If you do not wish to disclose, that's OK. Can I put down 'choose not to disclose' in your medical record? This means that you've chosen not to share this information at this time."

Case Study: Scaling SSOGI Data at Northwestern Medicine in Chicago

Implementing Sex Sexual Orientation Gender Identity (SSOGI) Data Collection in Cancer Care (SSOGI Collect)



SSOGI Collect: Specific Aims



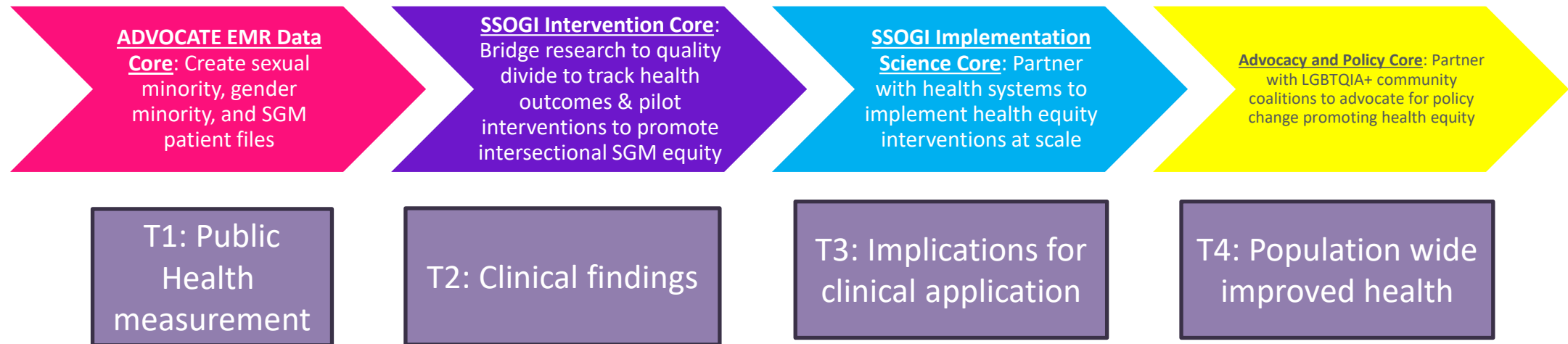
Aim 3: SSOGI Collection in NM Cancer Center Clinics

Cohort	Total	3/1/19 - 12/8/23					Total	12/8/23 - 2/21/24				
		LS	SAAB	SO	GI	Pronouns		LS	SAAB	SO	GI	Pronouns
Polsky Urology Clinic	3,031	100%	27.6%	23.5%	28.4%	42.7%	839	100%	32.2%	27.8%	32.8%	59.4%
Maggie Daley Women's Health Clinic	16,525	100%	28.8%	24%	30.9%	39.4%	3169	100%	32.8%	26.9%	35.6%	56%
All NM Patients	3,617,443	100%	8.3%	7.1%	10.9%	6.2%	778,210	100%	17.7%	14.8%	22.3%	15%

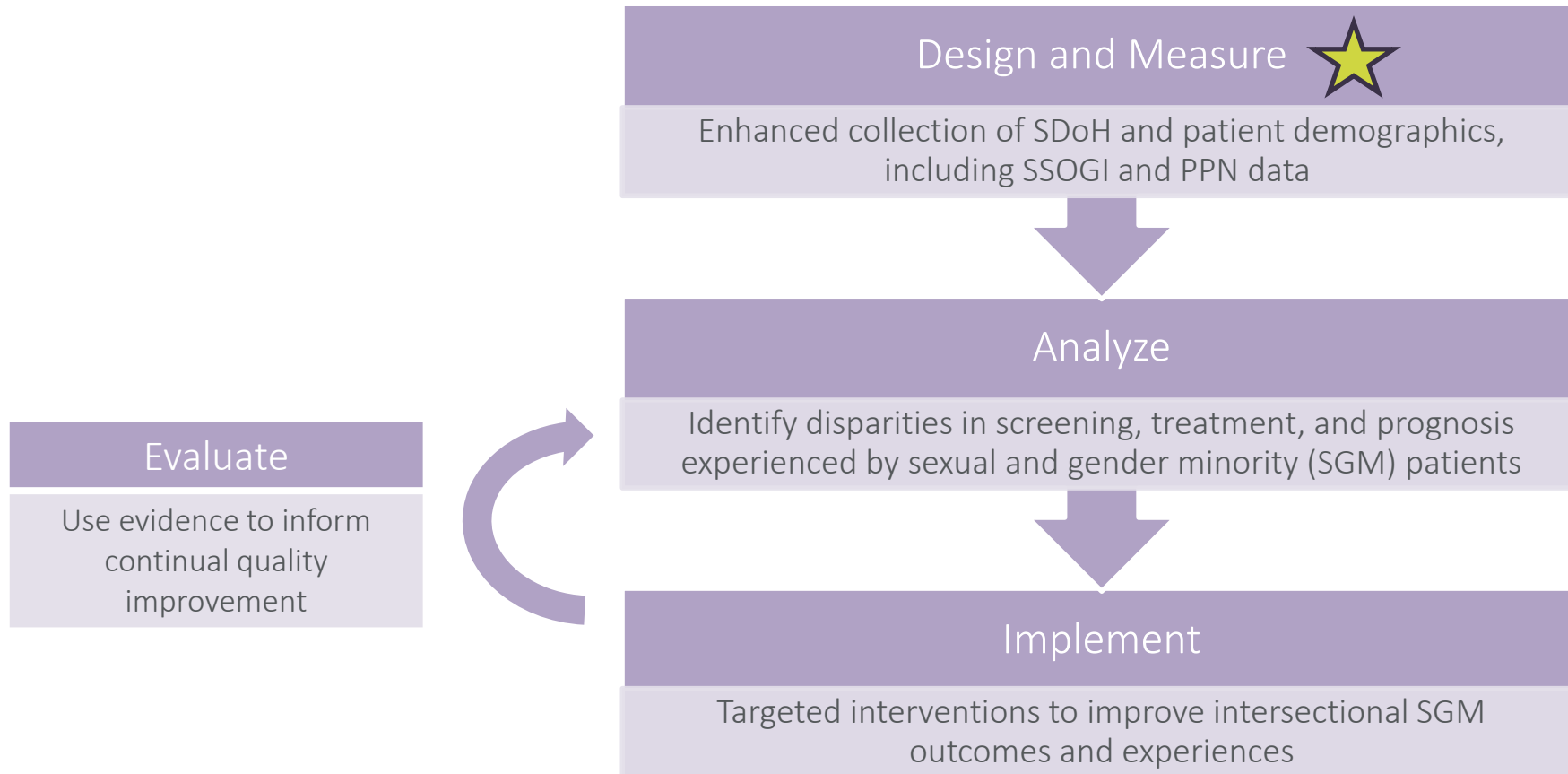
Table 2: Overview of patients with completion of legal sex (LS), sex assigned at birth (SAAB), sexual orientation (SO), gender identity (GI), and/or pronouns within the EMR by Lurie Cancer Center clinic location and all-comers to Northwestern Medicine since SSOGI SmartForm go-live until date of trainings and from date of trainings onward

ADVOCATE's Patient Care and Population Health Sciences Translational Model

Community, Patient, Provider, & Health System Engagement



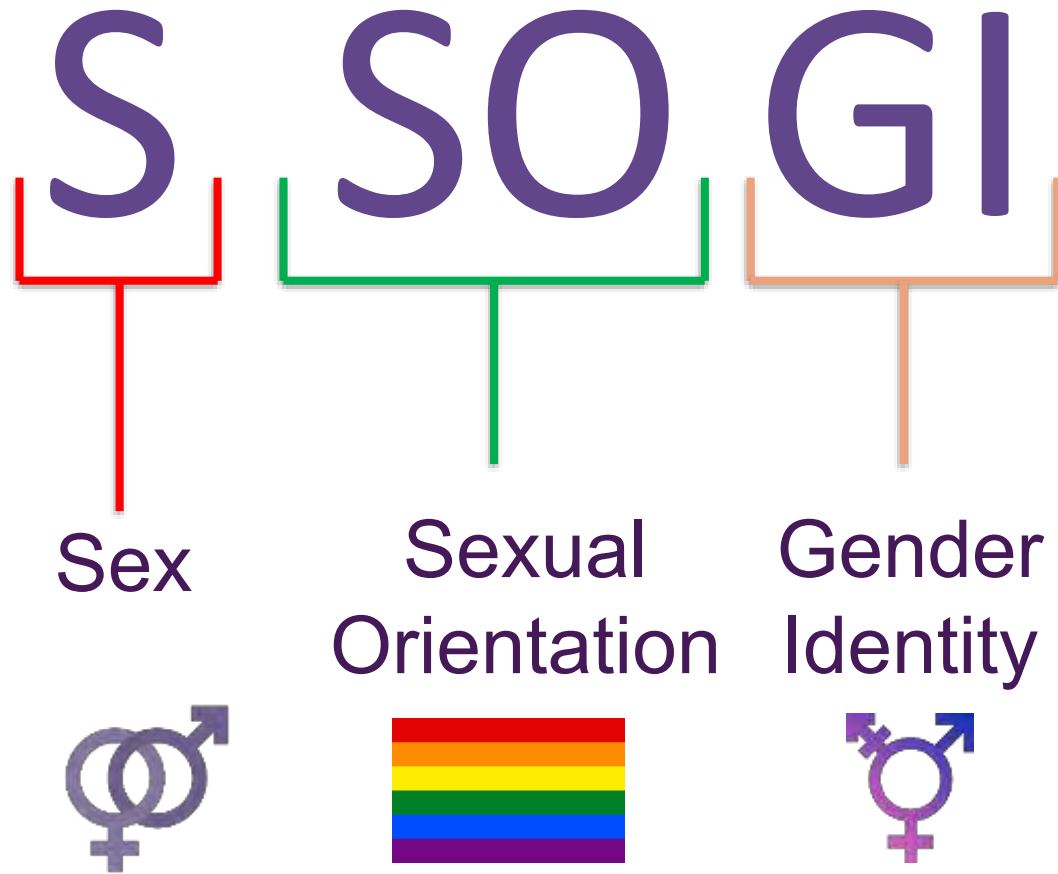
Laying Groundwork for a Learning Health System with NM Quality



Conclusion & Resources



Contact Information: Lauren.beach@northwestern.edu



Sex and Gender in Epic



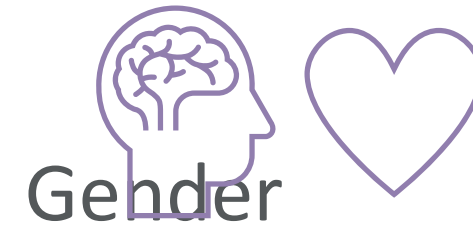
Legal Sex

The sex information listed on a person's ID, including passports, driver's licenses, birth certificate, and other forms of identification



Sex Assigned at Birth

The sex (male, female or intersex) assigned to an infant based on anatomical and other biological or genetic characteristics

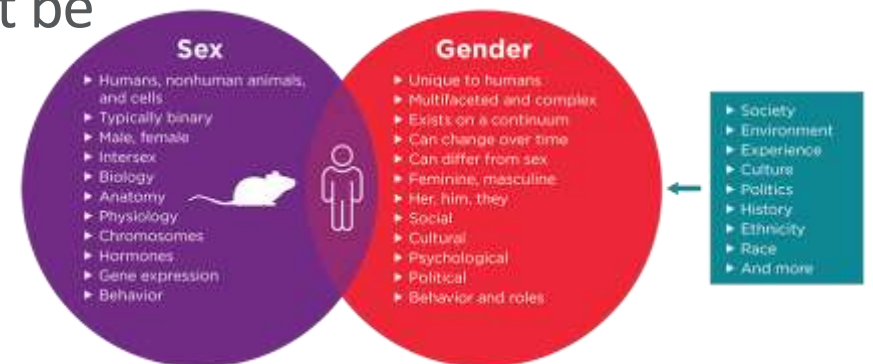


Gender Identity

One's innate understanding of their gender(s) that may or may not be the same as their sex assigned at birth

Dimensions of Sex

- Although sex is typically categorized within a binary, there is an expansive range of biological characteristics that have come to define sex
 - Genitals
 - Chromosomes
 - Secondary sexual characteristics (hair, breast development, etc)
 - Hormones
- Identity
 - It is important to recognize that sex itself is a social construct – assigning "male" to certain combinations of sex traits and "female" to others is in part a social decision
- "Natal" sex is what is assigned at birth, but may not be reflective of identity or biological reality!
 - "X" marker coming to Illinois id and driver licenses



Taconic Insights

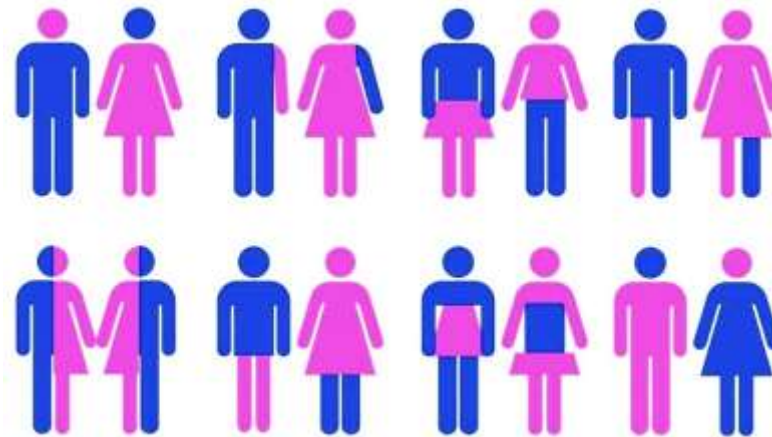
Dimensions of Gender

■ Gender identity

- A person's internal sense of their gender (do I consider myself a man, woman, non-binary, agender?)
- All people have a gender identity (though maybe not a label)

■ Gender expression

- How one presents themselves through their behavior, mannerisms, speech patterns, dress, and hairstyles
- May be on a variable spectrum



Gender identity vs. Gender expression

Key Terms



Intersex

An umbrella term describing variations in reproductive or sex anatomy in which the reproductive organs, genitals and/or other sexual anatomy do not develop according to traditional expectations for females and males



Transgender

Describes a person whose gender identity and sex assigned at birth do not correspond based on traditional expectations; for example, a person assigned female sex at birth who identifies as a man. Transgender can also include people with a nonbinary gender



Nonbinary

Describes a person whose gender identity falls outside of the traditional gender binary structure of girl/woman and boy/man

Variations in Gender

Transgender

- Both an Umbrella term and a specific identity
- Describes individuals whose gender identity does not align with the sex they were assigned at birth (SAB)
- Often associated with **medical or social transition**

Cisgender

- Refers to persons whose sex assigned at birth aligns with their gender identity

Non-Binary

- Both an Umbrella term and a specific identity
- Describes individuals who do not identify as either male or female
- May or may not involve medical or social transition

Gender-Affirming Care Basics

- Hormone therapy:
 - Masculinizing hormones
 - Testosterone: multiple forms of administration, including injectables, gels, and buccal tablets.
 - Can result in changes to voice, hair growth, and overall body composition.
 - Feminizing hormones
 - Spironolactone and estrogen
 - Can result in changes to breast development, prostate/teste atrophy, and overall body composition
- Surgical interventions
 - Top surgery
 - Masculinizing: mastectomy
 - Feminizing: breast augmentation
 - Bottom surgery
 - Masculinizing: oophorectomy, hysterectomy, phalloplasty, and/or vaginectomy.
 - Feminizing: vaginoplasty, orchiectomy, penectomy
 - Others: facial feminization, tracheal shaving, body contouring

Gender Identity Terminology

- Identity

- Do NOT use the following terms: "transgendered," "a transgender," "transgenders" , "transvestite," "tranny"
 - Instead, use: "transgender", "transgender individuals", "transgender person"

- Medical transition

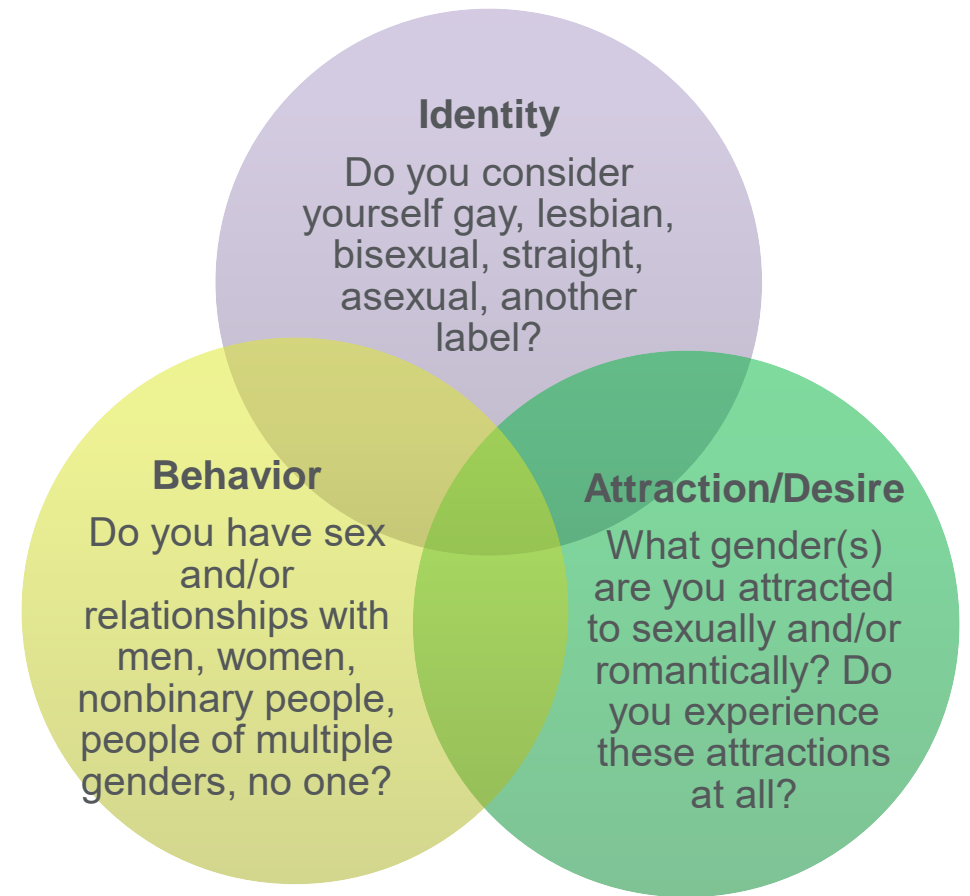
- Do NOT use the following terms "sex change," "sex-change operation"
 - Instead use "transitioned"; "He has medically transitioned"
- Do NOT use male-to-female (FTM) or female to male (MTF)
 - DO use transfeminine, transmasculine

- Common terms

- Queer: a term typically used by younger individuals as either (1) an umbrella term or (2) to describe an identity that is indefinite but not cis/hetero
 - Gender affirming hormone therapy/care

Dimensions of Sexual Orientation

Sexual orientation is an enduring pattern of romantic or sexual attraction (or a combination of these) to persons of a different gender, the same gender, or to multiple genders.



Variation in Sexual Orientation

Pansexual: attracted to all genders

Demisexual: requires emotional connection before sexual attraction



Gay



Lesbian



Bisexual



Pansexual



Progress Pride
Flag



Asexual



Demisexual



Aromantic