Ensuring Inclusion and Equity for Sexual and Gender Minority People in Patient-Centered Outcomes Research

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Building Data Capacity for Patient-Centered Outcomes Research:
An Agenda for 2021 to 2030
<u>Workshop 1</u>: Looking Ahead at Data Needs

My Identities & Pronouns

@ThePRIDEStudy
@MitchellLunn

Discussion Questions

1. What are the limitations of the PCOR data infrastructure in terms of:

- disparities in the data, including knowledge about patient outcomes, taking into consideration differences in patient preferences and values
- challenges associated with using the data to understand disparities and health equity
- lack of data on some populations

2. What are opportunities and priorities for enhancing data capacity in this area?

3. What data capacity challenges is HHS best positioned to address in the context of their public mission, authorities, programs, and data resources?

SGM Population Estimates

Americans' Self-Identified Sexual Orientation

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

	Among LGBT U.S. adults	Among all U.S. adults
	%	%
Lesbian	11.7	0.7
Gay	24.5	1.4
Bisexual	54.6	3.1
Transgender	11.3	0.6
Other (e.g., queer, same-gender-loving)	3.3	0.2

Percentages total more than 100% because respondents may choose more than one category.

GALLUP, 2020

United States™ Census Bureau

Sexual orientation and gender identity were **not** collected

SGM/LGBTQ+ people are a diverse, heterogenous group with differing health needs

THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

Three Main Concepts

Sexual Orientation [poorly collected in most clinical and research settings]

three constructs: identity, attraction, and behavior

Identity: sexuality with which someone identifies {bisexual, lesbian, straight, etc.}

Gender Identity [poorly collected in most clinical and research settings]

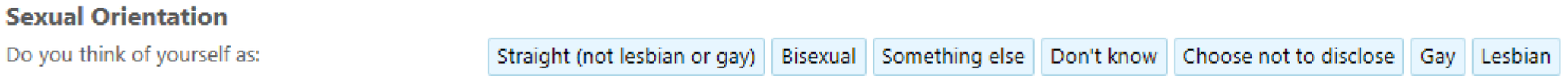
socially constructed roles, behaviors, activities, and attributes that society has defined as feminine, masculine {woman, man, etc.}

Sex Assigned at Birth

biological, anatomic, and physiological characteristics that primarily describe phenotype {female, male, intersex}

Clinical Setting and Data Models

Sexual Orientation: Stanford EHR



- Part of 2015 Base EHR Definition (2015 Health IT Certification Criteria)

- Only collects identity construct
- "Select one" only
- Limited selections compared to terms community uses (*e.g.*, queer)
- Write-in available

- No collection of sexual behaviors
  - Gender(s) of sexual partners
  - What organs are going where? (for appropriate STI risk assessment)
- No collection of sexual attraction (may be less clinically relevant)

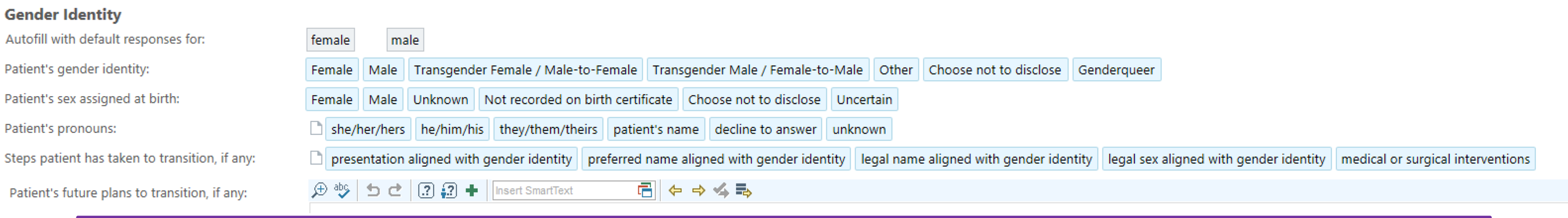
Sexual Orientation: PCORnet CDM v6

SEXUAL_ORIENTATION	RDBMS Text(2)	SAS Char(2)	AS=Asexual BI=Bisexual GA=Gay LE=Lesbian QU=Queer QS=Questioning ST=Straight SE=Something else MU=Multiple sexual orientations DC=Decline to answer NI=No information UN=Unknown OT=Other	Sexual orientation.	Source: Health IT Certification Criteria, 2015 Base Edition, modified with expert advisory within PCORnet https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base	

- Only records one entry
- Multiple selections are collapsed to “MU” (data loss)
- Write-in value lost.

- There are SNOMED codes for sexual orientations (very limited set).

Gender Identity: Stanford EHR



- Part of 2015 Base EHR Definition (2015 Health IT Certification Criteria)

- "Select one" only
- Limited selections (*e.g.*, non-binary, agender)
- Antiquated terms
- Write-in available

- Is there algorithmic support to identify transgender people who do not use "transgender" label based on sex assigned at birth? (respect for patient preferences)

Gender Identity: PCORnet CDM v6 & FHIR

GENDER_IDENTITY	RDBMS Text(2)	SAS Char(2)	M=Man F=Woman TM=Transgender male/Trans man/Female-to-male TF=Transgender female/Trans woman/Male-to-female GQ=Genderqueer/Non-binary SE=Something else MU=Multiple gender categories DC=Decline to answer NI=No information UN=Unknown OT=Other	Current gender identity.	Source: Health IT Certification Criteria, 2015 Base Edition, modified with expert advisory within PCORnet https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base	Use Genderqueer ("GQ") for patients who report a non-binary gender identify.

4.4.1.174.1 Content Logical Definition

This value set includes codes from the following code systems:

- Include these codes as defined in `http://hl7.org/fhir/gender-identity`

Code	Display	
male	male	the patient identifies as male
female	female	the patient identifies as female
non-binary	non-binary	the patient identifies with neither/both female and male
transgender-male	transgender male	the patient identifies as transgender female-to-male
transgender-female	transgender female	the patient identifies as transgender male-to-female
other	other	other gender identity
non-disclose	does not wish to disclose	the patient does not wish to disclose his gender identity

- Only records one entry
- Multiple selections are collapsed to "MU" (data loss)
- Write-in value lost.

Research Setting

Sexual Orientation: *All of Us* Research Program (NIH)

Sexual orientation is assessed with the following question:

Which of the following best represents how you think of yourself? (Check all that apply.)

- Gay
- Lesbian
- Straight; that is, not gay or lesbian, etc.
- Bisexual
- None of these describe me, and I'd like to see additional options*
- Prefer not to answer

[The following question is shown if the answer choice marked by * is selected.]

Are any of these a closer description of how you think of yourself? (Check all that apply.)

- Queer
- Polysexual, omnisexual, sapiosexual, or pansexual
- Asexual
- Two-spirit
- Have not figured out or are in the process of figuring out your sexuality
- Mostly straight, but sometimes attracted to people of your own sex
- Do not use labels to identity yourself
- Don't know the answer
- No, I mean something else (optional free-text field)

All of Us RESEARCH PROGRAM

- Only collects identity construct
- Created with community and SME input
- Multiple selections allowed

- Asked to all 1 million participants

- Menu → Submenu approach
  Can feel othering
- Write-in available

- Some antiquated terms
  (currently being revised)

Sexual Orientation: The PRIDE Study

CURRENT SEXUAL ORIENTATION (CHECK ALL THAT APPLY)

THE PRIDE STUDY

- ☐ Asexual
- ☐ Bisexual
- ☐ Gay
- ☐ Lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Questioning
- ☐ Same-gender loving
- ☐ Straight/Heterosexual
- ☐ Two-spirit
- ☐ Another sexual orientation

- Collects identity construct
  - Separate measures for sexual behavior and sexual attraction
- Multiple selections allowed
  ~35% select more than one
- Write-in available
- Revise terms every few years based on community engagement

Gender Identity: *All of Us* Research Program (NIH)

Gender identity is assessed with the following question:

What terms best express how you describe your current gender identity? (Check all that apply.)

- Man
- Woman
- Non-binary*
- Transgender*
- None of these describe me, and I'd like to consider additional options*
- Prefer not to answer

[The following question is shown if any answer choices marked by * are selected.]

Are any of these a closer description to your gender identity? (Check all that apply.)

- Transman/Transgender Man/FTM
- Transwoman/Transgender Woman/MTF
- Genderqueer
- Genderfluid
- Gender variant
- Two-Spirit
- Questioning or unsure of your gender identity
- None of these describe me, and I want to specify (optional free-text field)

All of Us RESEARCH PROGRAM

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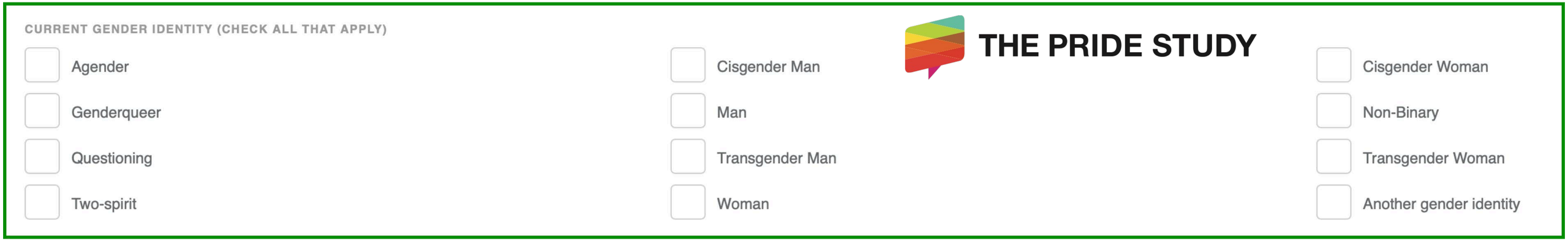
Gender Identity: The PRIDE Study



- Multiple selections allowed
  ~18% select more than one
- Write-in available

- Revise terms every few years based on community engagement

My Summary Thoughts

1. Current clinical approaches (EHR systems) and data models do not allow patients to comprehensively report their sexual orientation and/or gender identity.

2. Not using a patient's/participant's stated identity (*e.g.*, grouping or administratively classifying) will lose valuable data that may have health implications.

3. Research studies may serve has models for developing sexual orientation and gender identity data standards.

4. Sexual and gender minority terms rapidly change. Frequent re-evaluation with community engagement is critical to selecting optimal terms.


THANKS!
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END