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**Subject:** HHS LGBTQI+ Coordinating Committee \_ NASEM Presentation  
**Attachments:** NAS SGM Measurement Study Briefing HHS LGBTQI+ Coordinating Committee.pdf

*Sending on behalf of ADM Rachel Levine, Assistant Secretary for Health*

Hello LGBTQI+ Coordinating Committee Members,

Thank you all for attending Monday's meeting. As requested, I'm pleased to share the slides from the National Academies of Sciences, Engineering, and Medicine's presentation on the "Measuring Sex, Gender Identity, and Sexual Orientation" report. I can't emphasize enough how important the recommendations and results of this report are. Our LGBTQI+ stakeholders have resoundingly communicated the need and desire for more data, and I echo their request. I fully support these recommendations and offer any assistance needed in the implementation of the recommendations. I want to thank Dr. Karen Parker and the Office of Sexual & Gender Minority Research at NIH as they work to execute the recommendations. Dr. Parker and her team have also offered to answer any questions should folks need a resource. I look forward to our next meeting in June, Pride month, as we come together to celebrate the progress we've made and the progress to come.

Regards,

ADM Rachel Levine

**Rachel L. Levine, M.D.**

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COMMITTEE ON NATIONAL STATISTICS (CNSTAT)

# Measuring Sex, Gender Identity, and Sexual Orientation

*Committee on Measuring Sex, Gender  
Identity, and Sexual Orientation*

# Sponsor

- This work was sponsored by the National Institutes of Health (NIH)
  - Contract Number: HHSN263201800029I
  - Task Order Number: 75N98021F00001
- 19 entities within NIH provided funding for this project:

National Human Genome Research Institute  
National Institute on Aging  
National Institute of Allergy & Infectious Diseases  
*Eunice Kennedy Shriver* National Institute of Child  
Health & Human Development  
National Institute of Environmental Health Sciences  
National Institute of Mental Health  
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# Introduction

- Our identities shape opportunities, experiences with discrimination, and outcomes through our life course.
- Sex, gender, and sexual orientation are core aspects of identity; therefore, it is crucial that measures of these concepts accurately capture their complexity.
- Current data collection efforts in these areas are not standardized, leading to lack of conceptual precision and inability to compare studies. Advances in the conceptualization and measurement of sex and gender should be incorporated across scientific fields.
- Better measurement of sex, gender identity, and sexual orientation will also improve the ability to identify sexual and gender minority populations and understand the challenges they face.

# Statement of Task

1. Review current measures and the methodological issues related to measuring sex as a nonbinary construct, gender identity, and sexual orientation in surveys and research studies, in administrative settings, and in clinical settings.
2. Produce a consensus report with conclusions and recommendations on guiding principles for collecting data on sex, gender identity, and sexual orientation and recommended measures for these constructs in different settings.



# Organization of Report

- 1) Introduction, Definitions, and Scope of Report
- 2) Part I: Measurement Principles, Contexts, and Methods
- 3) Part II: Measure Recommendations

# Definitions

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# Definitions: Sex

- A multidimensional construct based on a cluster of anatomical and physiological traits (sex traits)
  - Sex traits include: external genitalia, secondary sex characteristics, gonads, chromosomes, and hormones
- Characteristics
  - Usually assigned as female or male
  - Most often defined at birth based on visual inspection of external genitalia
  - Sex traits usually assumed to be unambiguous, but may not be
  - Sex traits usually assumed to correspond to the same sex, but may not
  - Some sex traits can change or be altered over time

# Definitions:

## Populations Defined by Sex Traits

- Intersex/Differences in Sex Development (Intersex/DSD)
  - People whose sex traits do not all correspond to a single binary sex

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# Definition: Gender

- A multidimensional construct that links gender identity, gender expression, and social and cultural expectations about status, characteristics, and behavior that are associated with sex traits
  - Identity: A core element of a person's individual sense of self
  - Expression: How an individual signals their gender to others through behavior and appearance
  - Social and cultural expectations: Related to social status, characteristics, and behavior that are associated with sex traits
- Characteristics
  - Often conceptualized as binary (male/female or man/woman) in Western cultures, but also includes categories outside this binary
  - Often used interchangeably with sex, though it is conceptually distinct
  - Often assumed to be determined based on sex assigned at birth but may differ
  - Gender identity, expression, and social and cultural expectations may not all correspond to the same gender
  - May be temporally and contextually fluid

# Definitions: Gender Identities

- Transgender: A person whose current gender identity is different from the sex they were assigned at birth
  - Transgender experience: All people who can be classified as transgender, regardless of whether they identify as transgender
  - Transgender identity: People who identify as transgender
- Cisgender: A person whose current gender identity corresponds to the sex they were assigned at birth
- Nonbinary: An umbrella term for gender identities that lie outside the gender binary
  - Genderqueer: A person who does not follow gender norms
  - Genderfluid: A person who does not identify with a fixed gender
  - Two-Spirit: Placeholder term for specific gender and sexual orientation identities that are centered in Indigenous tribal worldviews, practices, and knowledges

# Definition: Sexual Orientation

- A multidimensional construct encompassing emotional, romantic, and sexual attraction, identity, and behavior
  - Identity: A person's core internal sense of their sexuality
  - Attraction: A multidimensional concept that includes the gender(s) to which a person is attracted and the strength of this attraction, including whether a person feels attraction at all
  - Behavior: A multidimensional concept that includes the gender(s) of sexual partners, specific sexual activities, and frequency of activity
- Characteristics
  - Often defined based on the gender(s) of a person's desired or actual partners relative to their own gender in Western cultures
  - The three dimensions of sexuality—attraction, identity, and behavior—may not correspond to the same orientation

# Definitions:

## Sexual Orientation Identities

- Straight or heterosexual: Sexually oriented toward people of a different, usually binary, gender
- Gay or homosexual: Sexually oriented toward people of the same, usually binary, gender (Note: The term “homosexual” can be considered offensive and outdated)
- Lesbian: Women who are sexually oriented toward other women
- Bisexual: Sexually oriented toward both men and women
- Queer: An umbrella term for belonging to the LGBTQI+ community; also used to refer to a person who is sexually oriented toward people of more than one gender
- Pansexual: Sexually oriented toward people of any gender
- Questioning: Uncertain about sexual orientation identity
- Two-Spirit: Placeholder term for specific gender and sexual orientation identities that are centered in Indigenous tribal worldviews, practices, and knowledges
- Same Gender Loving: Nonheterosexual sexual orientation identity used by some within African American communities as a resistance to Eurocentric language for sexuality



# Scope of Report

- Measures that can be used in the general English-speaking adult population
  - More detailed response options may be necessary for measures used within LGBTQI+ populations
  - Modifications to recommendations may be needed if they are used within younger populations
  - Also prioritized representation of indigenous sexual and gender minorities
- Focus on measures of identity that can also be used to identify sexual and gender minority populations

**Part I:**  
**Measurement Principles,  
Contexts, and Methods**

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# Data Collection Principles

- **Inclusiveness**
  - People deserve to count and be counted
- **Precision**
  - Use precise terminology that reflects the constructs of interest
- **Autonomy**
  - Respect individual identity and autonomy
- **Parsimony**
  - Collect only necessary data
- **Privacy**
  - Use data in a manner that benefits respondents and respects their privacy and confidentiality

# The Importance of Conceptual Clarity: Sex and Gender

- Conceptually distinct
- Each comprise multiple dimensions
- Conflating sex and gender or measuring either concept using a single binary measure can lead to mismeasurement or misuse of the data

# Conclusion 1

Gender encompasses identity, expression, and social position. A person's gender is associated with but cannot be reduced to either sex assigned at birth or specific sex traits. Therefore, data collection efforts should not conflate sex as a biological variable with gender or otherwise treat the respective concepts as interchangeable. In addition, in many contexts, including human subjects research and medical care, collection of data on gender is more relevant than collection of data on sex as a biological variable, particularly for the purposes of assessing inclusion and monitoring discrimination and other forms of disparate treatment.

# Recommendation 1

The standard for the National Institutes of Health should be to collect data on gender and report it by default. Collection of data on sex as a biological variable should be limited to circumstances where information about sex traits is relevant, as in the provision of clinical preventive screenings or for research investigating specific genetic, anatomical, or physiological processes and their connections to patterns of health and disease. In human populations, collection of data on sex as a biological variable should be accompanied by collection of data on gender.

# Data Collection Contexts

- Surveys and research
  - Includes data collected for population enumeration, social research, and demographic purposes
- Administrative
  - Vital statistics and other legal identification
  - Program and personnel administration
- Clinical/Health
  - Includes clinical data, electronic medical records, health surveys, public health surveillance, clinical trials research data

# Using Context-Specific Measures

- Much of the research is in survey research context
- Where possible, the panel evaluated measures that have been used in clinical and administrative settings
- Panel opted to recommend that the same measures be used within all three data collection settings, in absence of clear evidence indicating that poor performance or feasibility



# Panel's Measure Evaluation Criteria

- Questions

- Consistency with data collection principles
- Comprehensible within LGBTQI+ and general populations
- Tested within LGBTQI+ and general populations
- Consistent estimation across data collection contexts
- Tested using multiple administration modes
- Select one response

- Response Options

- Terminology is comprehensible within both LGBTQI+ and general populations
- Can measure recent trends
- Can track and incorporate changes in terminology
- Balances comprehensiveness with complexity
- Minimizes need to reclassify respondents
- Ordering follows generally accepted practices

**Part II:**  
**Measure Recommendations**

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# Sexual Orientation Identity: Recommended Measure

**RECOMMENDATION 2:** The panel recommends that the National Institutes of Health use the following question for assessing sexual orientation identity:

Which of the following best represents how you think of yourself? [Select ONE]:

- Lesbian or gay
- Straight, that is, not gay or lesbian
- Bisexual
- [If respondent is AIAN:] Two-Spirit
- I use a different term [free-text]
- (Don't know)
- (Prefer not to answer)

## What's different?

- Adding Two-Spirit
- Including write-in

# Sexual Orientation Identity: Measure Characteristics

## • Strengths

- Only measures identity
- Clearly distinguishes sexual orientation identities
- Enumeration of those who don't use labels
- Allows for culturally specific identification for Indigenous populations
- Tested within a diverse array of populations
- Tested within broad age range (ages 12-85)

## • Weaknesses

- Response set does not reflect current culture and terminology
- Write-in responses must be cleaned and coded
- Does not include response option that indicates uncertainty
- Uses negating language for straight category that is not conceptually accurate
- Response ordering does not reflect standard criteria

# Sexual Orientation Identity: Topics for Future Research

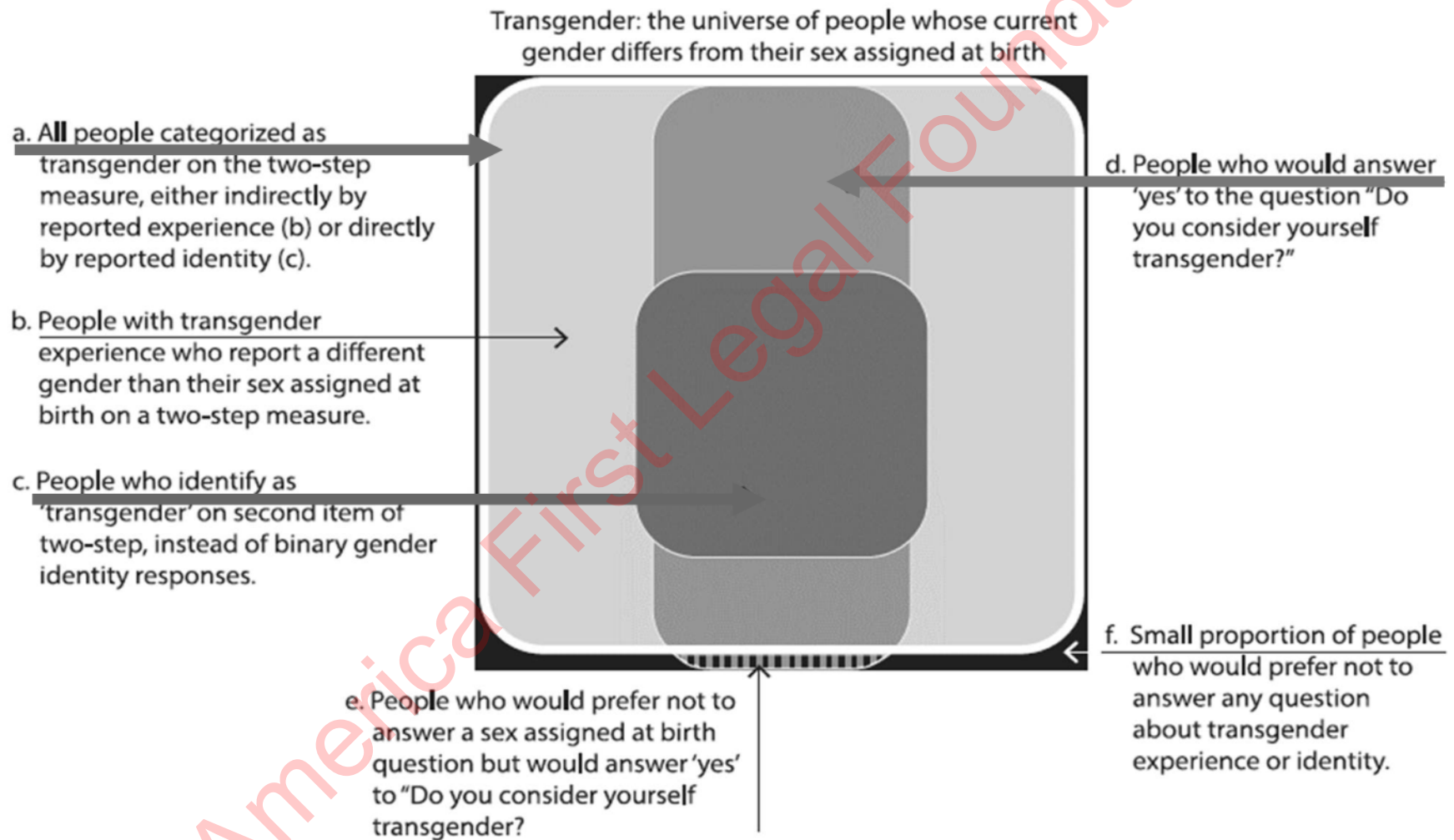
**RECOMMENDATION 3:** To further improve the quality and inclusivity of current measures of sexual orientation identity, the National Institutes of Health should fund and conduct research on the following topics:

- Alternate wording for the “straight” response option
- The ordering of response categories
- The addition of response options such as: “queer,” “questioning,” and “same gender loving”
- Guidelines for measuring sexual orientation attraction and behavior
- Best practices for collecting sexual orientation information within adolescent populations
- Proxy reporting of sexual orientation identity

# Measuring Gender and Identifying Transgender Populations

- Existing measures:
  - **Standard binary sex/gender**
    - Single item: male and female answer options only
    - Does not distinguish cisgender or transgender people, does not allow for nonbinary sex or gender
  - **Including transgender people**
    - **One-step:** Single question asking whether respondents consider themselves transgender (or identify as male, female or transgender)
    - **Two-step:** Two questions, usually sex assigned at birth and current gender identity
- Existing research supports a two-step approach:
  - Enumerates both cisgender and transgender people
  - Also accounts for both transgender experience and identity
    - Not all transgender people identify explicitly as transgender

# Conceptual and Empirical Distinctions for Transgender Measures



# Two-Step Sex and Gender: Recommended Measure

**RECOMMENDATION 4:** The panel recommends that the National Institutes of Health use the following pair of questions assessing sex assigned at birth and gender identity:

Q1: What sex were you assigned at birth, on your original birth certificate?

Female

Male

(Don't know)

(Prefer not to answer)

Q2: What is your current gender? [Mark only one]

Female

Male

Transgender

[If respondent is AIAN:] Two-Spirit

I use a different term: [free text]

(Don't know)

(Prefer not to answer)

## What's different?

- Wording of GI stem
- Adding Two-Spirit
- Including write-in
- Female first ordering



# Two-Step Sex and Gender: Measure Characteristics

## • Strengths

- Clearly distinguishes between sex assigned at birth and current gender
- Cross-tabulation allows enumeration of cisgender and transgender people
- Allows for culturally specific identification for Indigenous populations
- Tested within a diverse array of populations, including a broad age range (ages 12-85)

## • Weaknesses

- Gender response set is forced choice, but response options are not mutually exclusive
- Write-in responses must be cleaned and coded
- Newer gender terminology not included as response option
- Sex assigned at birth does not include nonbinary option
- Sex assigned at birth may be sensitive for some and inappropriate to include in some circumstances

# Two-Step Sex and Gender: Topics for Future Research

**RECOMMENDATION 5:** To improve the quality and inclusivity of the recommended two-step gender measure—sex assigned at birth and current gender—the National Institutes of Health should fund and conduct research on the following topics:

- The use of gender-based response options (man/woman) and optimal response ordering
- Alternative two-step measures that can be used in circumstances in which asking about sex assigned at birth is inappropriate
- Replacing the gender response option “transgender” with “nonbinary”
- The need for a “nonbinary” response option for sex assigned at birth
- Best practices for collecting two-step sex and gender information from youth, people with limited English proficiency, and with proxy reporting

# Intersex Status

**CONCLUSION 2:** Intersex status is an important component of demographic status, private medical information, and an aspect of identity. Although there are barriers to disclosure, people appear to want to disclose their status.

Because of historical, legal, and medical factors, almost no person in the United States is assigned intersex at birth. Therefore, it is inappropriate to assess intersex status primarily with an “intersex” response option for sex assigned at birth; however, when sex assigned at birth is asked, it may be appropriate to include “prefer not to answer” or “do not know” options.

# Recommendation 6

When the National Institutes of Health seeks to identify people with intersex traits or differences of sex development in clinical, survey, research, and administrative settings, they should do so by using a standalone measure that asks respondents to report their intersex status. They should not do so by adding “intersex” as a third response category to a binary measure of sex.

# Intersex/DSD Status Measures with the Strongest Evidentiary Support

- Very little evidence on the quality of intersex/DSD status measures is available.
- Three question stems have been tested in population-based surveys:
  - *Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?*
  - *Were you born with a variation in your physical sex characteristics? (This is sometimes called being intersex or having a difference in sex development, or DSD.)*
  - *Have you ever been diagnosed by a medical doctor with an intersex condition or a difference of sex development'?*

# Intersex/DSD Status: Preferred Measure

CONCLUSION 3: Based on the best available evidence, community guidance, and expert opinion, intersex status can be measured using the following question:

Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?

Yes

No

(Don't know)

(Prefer not to answer)

# Intersex/DSD Status: Topics for Future Research

RECOMMENDATION 7: To improve the quality and inclusivity of current measures of intersex status, the National Institutes of Health should fund and conduct research on the following topics:

- The use of a single-item intersex/DSD status question
- The relative quality of the three measures of intersex/DSD status identified by the panel
- The effects of using terminology such as “intersex” or “DSD” or definitions of these terms in question stems or supplemental text
- The prevalence of “intersex” as a gender identity term among people with intersex traits
- Proxy reporting of intersex/DSD status, particularly by parents

# Thank you!

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CONSENSUS STUDY REPORT

Measuring **Sex,**  
**Gender Identity,**  
and **Sexual Orientation**

## Access The Report:

<https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>

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