Progress in SOGI Data Collection: Implementing the NASEM Report

Kellan E. Baker, PhD, MPH, MA

- Executive Director, Whitman-Walker Institute
- Member, NASEM Committee on Measuring Sex, Gender Identity, and Sexual Orientation for the National Institutes of Health

kbaker@whitman-walker.org



NASEM 2022 SOGI Report Sponsors

This report was sponsored by 19 Institutes, Centers, and Offices across NIH:

- 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
- National Institute of Minority Health & Health Disparities
- National Institute of Neurological Disorders & Stroke
- Office of the Director, All of Us
- Office of the Director, Chief Officer for Scientific Workforce Diversity

- Office of the Director, Division of Program Coordination, Planning, & Strategic Initiatives:
 - Office of AIDS Research
 - Office of Behavioral and Social Sciences Research
 - Office of Disease Prevention
 - Office of Research on Women's Health
 - Office of Strategic Communication
 - Sexual & Gender Minority Research Office
- Office of the Director, Office of Equity, Diversity, & Inclusion
- Office of the Director, Office of Intramural Research, Office of Intramural Training and Education





Sciences Engineering Medicine

Statement of Task

- 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.
- 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.



Scope of the Report

- Measures than 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
- Three domains: surveys and research, administrative settings, and clinical settings



Recommendation: 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)



Sexual Orientation: 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



Recommendation: 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)



Cross Tabulation of Two-Step Measure

- Cisgender women (female/female)
- Cisgender men (male/male)
- Transgender women (male/female)
- Transgender men (female/male)
- People who can be classified as transgender (trans men, trans women, people who identify using the term "transgender")
- People with nonbinary gender identities (Two-spirit, write-ins)
- GENDER IDENTITY AND GENDER MODALITY



Gender Identity: Topics for Future Research

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

- Gender-based response options (man/woman) and optimal response ordering
- Performance of a "select all that apply" approach for current gender
- Replacing or augmenting the response option "transgender" with "nonbinary"
- Categorization of nonbinary people vis-à-vis transgender status or identity
- The need for a "nonbinary" response option for sex assigned at birth
- Stability of responses over time
- Alternative two-step measures that can be used in circumstances in which asking about sex assigned at birth is inappropriate
- Best practices for collecting two-step sex and gender information from youth, people with limited English proficiency, and with proxy reporting

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



2011: Obama 1990: Census adds 1999: NHANES adds 2010: Census reports **Administration** "unmarried couple" sexual orientation first count of same-sex releases LGBT Data married couples question option **Progression Plan** 2016: FCSM releases 2013: NHIS adds sexual 2015: NCVS adds 2014: BRFSS offers first reports on SOGI in orientation identity sexual identity SOGI module the Federal Statistical question question **System** 2022: Biden 2022: NASEM releases 2016: SOGI questions 2021: Household Pulse **Administration** Measuring Sex, Gender proposed for American Survey adds SOGI **Executive Order 14075** Identity, and Sexual **Community Survey** questions requires agency SOGI Orientation for NIH **Data Action Plans** 2023: OMB releases Recommendations on 2023: White House 2023: Census testing 2023: Federal agencies SOGI questions for the the Best Practices for releases Federal develop SOGI data the Collection of SOGI Evidence Agenda on **American Community** action plans Data on Federal LGBTQI+ Equity Survey

Statistical Surveys

JUNE 15, 2022

Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals

Sec. 11. Promoting Inclusive and Responsible Federal Data Collection Practices. (a) Advancing equity and full inclusion for LGBTQI+ individuals requires that the Federal Government use evidence and data to measure and address the disparities that LGBTQI+ individuals, families, and households face, while safeguarding privacy, security, and civil rights.



FEDERAL EVIDENCE AGENDA ON LGBTQI+ EQUITY

- (b) To advance the responsible and effective collection and use of data on sexual orientation, gender identity, and sex characteristics (SOGI data), the Co-Chairs of the Interagency Working Group on Equitable Data established in Executive Order 13985 of January 20, 2021 (Advancing Racial Equity and Support for Underserved Communities Through the Federal Government), shall, within 30 days of the date of this order, establish a subcommittee on SOGI data to coordinate with agencies on strengthening the Federal Government's collection of SOGI data to advance equity for LGBTQI+ individuals. Within 120 days of the date of this order, the subcommittee shall, in coordination with the Director of OMB, develop and release a Federal Evidence Agenda on LGBTQI+ Equity, which shall:
- (i) describe disparities faced by LGBTQI+ individuals that could be better understood through Federal statistics and data collection;
- (ii) identify, in coordination with agency Statistical Officials, Chief Science Officers, Chief Data Officers, and Evaluation Officers, Federal data collections where improved SOGI data collection may be important for advancing the Federal Government's ability to measure disparities facing LGBTQI+ individuals; and

RECOMMENDATIONS ON THE BEST PRACTICES FOR THE COLLECTION OF SEXUAL ORIENTATION AND GENDER IDENTITY DATA ON FEDERAL STATISTICAL SUR

Pursuant to the June 2022 Executive Order 14075 on Advancing Equality for Lesbian, Gay, Bisexual

Tra (e) Within 180 days of the date of this order, to support agencies in appropriately collecting and using SOGI data, the Director of OMB, through foi sta the Chief Statistician of the United States, shall publish a report with an recommendations for agencies on the best practices for the collection of SOGI data on Federal statistical surveys, including strategies to preserve data Th ite privacy and safety. gu

research. It is not the intent of this report to limit the continued evolution and improvement of data collection methods.

(c) Within 200 days of the date of this order, the head of each agency that conducts relevant programs or statistical surveys related to the Federal Evidence Agenda on LGBTQI+ Equity shall submit to the Co-Chairs of the Interagency Working Group on Equitable Data a SOGI Data Action Plan, which shall detail how the agency plans to use SOGI data to advance equity for LGBTQI+ individuals and shall identify how the agency plans to implement the recommendations in the Federal Evidence Agenda on LGBTQI+ Equity.

Sexual Orientation and Gender Identity (SOGI)

Data Action Plan for the Department of Housing
and Urban Development

