Maternal and Reproductive Health: Sex and Gender Minority Inclusion

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Language has the power to shape what we think, and how we think has the power to shape what we do.

Language is open to criticism for being non-inclusive of the full range of sexualities, gender identities, gender expressions and family arrangements.

Can erase and render invisible the caregiving and reproductive capacities and experiences of lesbian mothers and gay fathers and their partners, gender queer and gender non-conforming and trans individuals.
Critical reflection

Reexamine our assumptions, language, practices and policies that reinforce the idea that caregiving, nurturing and particular reproductive capacities are the privilege of some but not others.

The gendering of our language doesn’t exist in a vacuum – experiences are gendered and need to be explored.

Language needs to make visible connections between the body, sex, gender, and caregiving -- this is not just true for cisgender straight women but for those whose gender identity and sexual orientation are outside this binary box.
• **Journal of Human Lactation** – introducing new sex and gender-inclusive language guidelines and policies to better align with movements toward greater health equity and social and publication ethics.
  • The aim of this policy is to facilitate higher quality publications and gender and sex inclusivity.

• Other professional journals and associations have developed policies and approaches for maintaining gender equity.

• In 2012, the *European Association of Science Editors* undertook an extensive process to develop the *Sex and Gender Equity in Research* Guidelines which provide researchers with an excellent discussion of how gender and sex permeate all aspects of the research project.
• **Sex and gender** should consider them as two separate variables and should use appropriate terminology.

• Authors who have not addressed sex and gender identity separately in conceptualizing or conducting their study may be asked to provide a rationale for why this issue was not addressed. If sex and gender data were not collected, assumptions should not be made or reported.

• If sex or gender data could have been relevant but the research team was not able to collect it, this is a limitation of study design and should be addressed in the limitations section.

• Any words or language that implies or ascribes binary (male/female) gender should only be used to describe people whose gender identity is known to match those terms (e.g., mother/father, maternal/paternal, and wife/husband). If gender identity is not known, non-gendered options should be used (e.g., parent, parental, and spouse/partner).

• Authors may not use terms that imply or that rely on assumptions that sex and gender are exclusively binary structures (e.g., “he/she” and “opposite sex”).

• Current terms and definitions need to be used throughout the manuscript when discussing sex and gender. These terms may require operationalized definitions (e.g., “mother”).
Decision Points:

Sex and Gender Minority (SGM) Inclusion

Topic SGM Relevant?

No? Justify

Yes

Study Designs

Partnerships, Collaborators

Conceptualizations

Dissemination

Samples, Measurements

Data Disaggregation

Discussion/ Limitations
SOGI AND MEASUREMENT IN CONCEPTUALIZING RESEARCH
**RECENT WORK:**

**LGBT-CAT**

- **QUAL/QUANT**
- **PRE-/POST-**
- Validation opportunity
- Multiple adaptations
ONGOING CONSIDERATIONS

- Measuring SO through identity or behavior?
- Terms change very quickly in literature
- Terms people use may change (moving target)
- Terms are not mutually exclusive
- Terms need to be the same to compare variables between studies
### Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys

<table>
<thead>
<tr>
<th>Topic asked: 2001-present</th>
<th>(O/R) Do you think of yourself as...</th>
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<tbody>
<tr>
<td>Current Question:</td>
<td>Heterosexual or straight</td>
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<td></td>
<td>Homosexual or Gay</td>
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<td></td>
<td>[If R is female then Lesbian]</td>
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<td>Bisexual</td>
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<td>Something else</td>
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<td>Years asked:</td>
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<td>Current Question:</td>
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<td>2006-2013</td>
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<th>Halized population aged 18-59</th>
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<tr>
<th>NSFG (DHHS/CDC/NCHS)</th>
<th>ACASI</th>
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<tr>
<td>(O/R) Do you think of yourself as...</td>
<td>U.S. adult civilian, noninstitutionalized population aged 15-44</td>
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<td>Heterosexual or straight</td>
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ADVANCES IN MEASUREMENT (II/II)

- NIH
- Best practices
- Working Group
- Common Measures
- Emerging protocols (like PhenX)

The NIH Sexual & Gender Minority Research Office (SGMRO) recognizes the growing need to develop better measures and methods to accurately capture and understand the health of sexual and gender minority (SGM) populations. The information provided highlights work within the field of SGM methods and measurement. These resources are not exhaustive. They may be useful for those looking to better understand how to capture SGM populations in research and clinical settings but do not represent standards required by NIH.

Data and Measurement Frameworks

- **Data Sources**
  Access publicly-available, nationally-representative data sources that can be used to answer your SGM-related health research questions.

- **Examples of Sexual Orientation and Gender Identity (SOGI) Questions**
  Find previously-used demographic and other questions that capture sexual identity, sexual attraction, sexual behavior, and gender identity.

- **Publications**
  Read publications related to SGM measurement research.

Quick Links

- Data Sources
- Examples of Sexual Orientation and Gender Identity (SOGI) Questions
- Federal Register Notice PDF version
- Publications
- SGM Related Projects (via NIH RePORTER)
- NIH PhenX Toolkit SOGI Protocol
- Measuring Sexual Orientation and Gender Identity Research Group
- Data Sharing for Demographic Research
- CMS SGM Clearinghouse (Surveys with SGM Topics/Questions)

Related Federal Reports

- Current Measures of Sexual Orientation and Gender Identity (SOGI)
FUTURE DIRECTIONS IN MEASUREMENT

- PRIDE Study
- Customization on-demand
- CBPR
- Intersectionality
RESOURCES

- Gender Elephant: https://www.doyoutools.org/breaking-the-box
- NIH SGMRO Methods and Measurement in Sexual & Gender Minority Health Research: https://dpcpsi.nih.gov/sgmro/measurement
- NIH Examples of Sexual Orientation and Gender Identity (SOGI) Questions: https://dpcpsi.nih.gov/sgmro/measurement/questions
- NIH PhenX Toolkit: https://www.phenxtoolkit.org/search/results?searchTerm=gender&searchtype=smartsearch

NIH FOA Research on the Health of Transgender and Gender Nonconforming Populations (R01 Clinical Trial Optional) includes “Improved Methodology and Measurement”
Reflection and Conversation Starters

1. Are the journals in your area also moving in this direction?

2. How do we change our research paradigms and approaches to be more inclusive?

3. How do we do (2) without doing harm to the LGBTQ community?
   a) What do we have to learn?
   b) What do we need to do different?
   c) Who do we need to partner with and how do we develop those relationships?

4. SGM inclusion is related to racial equity: how do we bring both a racial and gender equity lens? —black and brown LGBTQ folks are very marginalized and vulnerable

5. How can we continue this conversation?