

Summary of Comments on Methods and Measurement in Sexual & Gender Minority Health Research: *Identifying Research Opportunities*

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Introduction

The Sexual & Gender Minority Research Office (SGMRO), within the Division of Program Coordination, Planning, and Strategic Initiatives at the National Institutes of Health (NIH), developed a report pertaining specifically and exclusively to methods and measurement research in sexual and gender minority (SGM) health. Experts in the field identified research opportunities related to methods and measurement in SGM health research during a workshop held in the spring of 2018. The report, entitled *Methods and Measurement in Sexual & Gender Minority Health Research: Developing a Research Agenda and Identifying Research Opportunities*, which reflects the content of the discussion among participants at the workshop, has been posted to the SGMRO website. This report does not represent the official position of the NIH or any other government agency.

Content Covered in the Workshop

In April 2018, the SGMRO hosted a workshop entitled “Methods and Measurement in Sexual & Gender Minority Health Research: Identifying Research Opportunities” that covered three areas of SGM-related research: measurement of SGM status, measurement of related constructs, and sampling. For each of these primary topics, experts in the field considered the current state of research and identified several research opportunities that, if explored, would advance the field of SGM-related measurement research.

- I. Measurement of SGM Status.** This category included: Sexual Orientation (identity, behavior, attraction); Gender Identity (cisgender, gender nonconforming, man, non-binary, transgender, woman); Disorders or Differences of Sex Development (DSD) or Intersex (medical diagnosis vs. self-identified); Fluidity (identity across contexts, time, and developmental stage); Assessment Modality (self-report, collection from a provider, on the phone, Internet, paper); and Clinical Settings.
- II. Measurement of Related Constructs.** This category included: Stigma (structural, interpersonal, individual or internalized); Coming Out and Disclosure Process; Family Relationships; and Cultural Competence and Humility in the Health Care and Research Settings (providers, facilities, etc.).
- III. Sampling.** This category included: Probability vs. Non-Probability Sampling; Sampling Across Demographics and Sub-Populations; and Small Sample Sizes.

To obtain additional comments on the specific components of this document for the purposes of informing and enhancing its content, a [public notice](#) was published in the *Federal Register* on March 15, 2019. The deadline for comments was April 15, 2019. Comments received during that period are summarized here.

To best inform the final document, comments were specifically requested on the following questions:

- (1) What are the most important and relevant methods and measurement-related research questions to members of the SGM community?
- (2) What are the key methods and measurement-related research questions missing from the research opportunities that should be included?

Public Comments

Question 1 Responses

Below is a summary of public comments in response to the specific question posed.

(1) What are the most important and relevant methods and measurement-related research questions to members of the SGM community?

One respondent noted the continued need for probability sampling. They further stated that it comes as a surprise to many policymakers, researchers, and advocates working outside the lesbian, gay, bisexual, transgender, and queer and two spirit (LGBTQ2S) context that there is still a lack of many large, nationally representative surveys of LGBTQ2S people. For better or worse, these types of surveys are considered by many decision makers as the “gold standard.” It is imperative that work to expand research about LGBTQ2S people and their experiences utilize these types of samples. Probability samples increase the use of the data and its findings beyond the merely academic context and are critical for moving forward policies that can improve the lives of LGBTQ2S people and their families.

In addition, it was noted that oversampling people of color is important. Given recent findings from Gallup’s Daily Tracking Poll, more than two in five LGBTQ2S people are people of color and people of color are, in fact, more likely to identify as LGBTQ2S than white people. Therefore, it is important that surveys about LGBTQ2S people and their experiences include an oversampling of communities of color. For example, the lack of information about Asian and Native Hawaiian and Other Pacific Islander (NHOPI) LGBTQ2S people, including the inability to disaggregate data by race and ethnicity, continues to be limiting in understanding and addressing disparities.

Question 2 Responses

Below is a summary of public comments in response to the specific question posed.

(2) What are the key methods and measurement-related research questions missing from the research opportunities that should be included?

One respondent noted the importance of including the specific language “socio-cultural and socio-structural factors” in measurement of related constructs and enumerating community/collective trauma as part of the summary where other forms of trauma are mentioned.

Other Responses

This section summarizes comments from the public that do not appear to pertain to the questions asked in the Federal Register announcement.

One response from international colleagues provided detailed information on DSD in the form of a report. The information provided addressed the complexity and breadth of DSD-related research. The respondent further stated that the use of the term “disorders of sex development” is not recommended due to the policy implications of the medically unnecessary hormonal and surgical interventions that this framing promotes.

One comment stated that funding used on SGM populations would be better spent on other disease areas/conditions, and not on measurement.

A respondent commented that they hoped sufficient funding would follow this request for additional information.

Another respondent posted the question: Are there methods more effective in this population than in the heterosexual population for intervention trials and treatment of depression? We know from the research that lesbian women use more psychotherapy than anti-depressant medication for depression, but the reasons are not well understood. We need to determine if the perinatal depression screen used ([Edinburgh, PHQ9](#)) is effective in lesbian and bisexual women who are pregnant and postpartum.

Another respondent made specific edits to page 2 of the document. Under the section, *Measurement of SGM Status*, “clinical setting” should be made to include “provider knowledge,” which also should be included under the section on *Measurement of Related Constructs*; “cultural competence/humility” should be included as there is an epistemic embedded binary construct to medical education that promulgates a lack of provider knowledge and thereby skill set and comfort in providing care, or worse, enacted stigma, to the SGM individuals.

Another respondent posed specific questions:

- Why do lesbian women have more asthma when corrected for smoking and obesity?
- What is the prevalence of postpartum depression in the SGM population? What are the most effective methods for screening and treatment?
- What can we learn about obstetrics/gynecology outcomes among this population?
- What is the most effective educational method to decrease bias among health professionals against members of the SGM community?

Conclusion

The NIH will work across its Institutes, Centers, and Offices to ensure that the feedback summarized in this document from researchers, the nonprofit community, professional societies, and the general public is taken into consideration as it works to implement improvements in the measurement of SGM populations.

