National Institutes of Health
Sexual & Gender Minority Research Office

Methods and Measurement in Sexual & Gender Minority Health Research:

Developing a Research Agenda and Identifying Research Opportunities

April 3 – 4, 2018

Introduction

In 2015, the National Institutes of Health (NIH) established the Sexual & Gender Minority Research Office (SGMRO) in the Division of Program Coordination, Planning, and Strategic Initiatives in the Office of the Director. The role of the SGMRO is to: coordinate sexual and gender minority (SGM)[1] health research activities across the NIH; represent the NIH at conferences and events on trans-NIH activities focused on SGM research; coordinate and convene conferences and workshops to inform priority setting and research activities; collaborate with NIH Institutes, Centers, and Offices (ICOs) on the development of SGM health research reports; manage information dissemination related to SGM research; and work with NIH ICOs to leverage resources and develop initiatives to support SGM health research.

The 21st Century Cures Act, signed into law on December 13, 2016, included SGM-specific provisions, by amending the Public Health Service Act, SEC. 404N. [283] POPULATION FOCUSED RESEARCH. Those provisions are summarized as follows:

> The Director of the National Institutes of Health shall, as appropriate, encourage efforts to improve research related to the health of sexual and gender minority populations, including by: facilitating increased participation of sexual and gender minority populations in clinical research supported by the National Institutes of Health, and reporting on such participation, as applicable; facilitating the development of valid and reliable methods for research relevant to sexual and gender minority populations; and addressing methodological challenges.

As a result of the growing need to develop better measures and methods to accurately capture and understand the health of SGM populations, the SGMRO brought together experts from a variety of fields to outline research opportunities in SGM-related methods and measurement. This document reflects the content of the discussion among participants at the workshop and does not represent an official position of the NIH or any other government agency.

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[1] Sexual and gender minority is an umbrella term utilized by the NIH that encompasses lesbian, gay, bisexual, and transgender populations as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional, societal, cultural, or physiological norms. This includes individuals with disorders or differences of sex development (DSD), sometimes known as intersex.

Participants and Structure of Workshop

In April of 2018, the SGMRO hosted a 1.5-day workshop to identify research opportunities in SGM-related methods and measurement. The planning committee included both NIH staff and extramural researchers who designed the workshop agenda and developed a schema to guide the discussions (see **Appendix 1**).

The workshop focused on three areas: (1) measurement of SGM status; (2) measurement of core SGM health constructs; and (3) sampling. The workshop was conducted primarily via breakout sessions that incorporated large blocks of time for discussion. Extramural researchers who were invited represented various research areas, stages of career, populations of interest, and disciplines. Community members, NIH staff, and other federal staff were also included. Discussions focused on various concepts under each of the domains identified by the planning committee; overarching themes of intersectionality, life span, culture, and historical context and cohort effects were considered throughout the discussions and across each breakout session. The need for a deeper understanding of how to measure equity and intersectionality were also highlighted as core issues in SGM-related methods and measures. The concepts for consideration, as identified by the planning committee, are highlighted below.

Measurement of SGM Status

Overarching themes: intersectionality, life span, culture, and historical context and cohort effects

- Sexual Orientation (identity, behavior, attraction)
- Gender Identity (cisgender, gender nonconforming, man, non-binary, transgender, woman)
- Disorders or Differences of Sex Development (DSD)/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)
- Clinical Settings

Measurement of Related Constructs

Overarching themes: intersectionality, life span, culture, and historical context and cohort effects

- Stigma (structural, interpersonal, individual or internalized)
- Coming Out/Disclosure Process
- Family Relationships
- Cultural Competence/Humility in the Health Care and Research Settings (providers, facilities, etc.)

Sampling

Overarching themes: intersectionality, life span, culture, and historical context and cohort effects

- Probability vs. Non-Probability Sampling
- Sampling Across Demographics/Sub-Populations
- Small Sample Sizes

RESEARCH OPPORTUNITIES IDENTIFIED:

Measurement of SGM Status

The research opportunities highlighted below were considered by the workshop participants to be the areas of greatest need for better understanding how to measure SGM status. Discussion focused on context, stability of measures over time, proxy reporting, intersex identity, perceived discrimination, interoperability across electronic health records (EHRs), perceived SGM status, and asexual populations. The following is not an exhaustive list of research questions to be explored.

- Design methods to ascertain SGM status, taking into consideration cross-cultural contexts including race, ethnicity, language, age, nationality, geography, and religion.
- Develop ways to measure SGM status that are stable over time and across generations, given cultural and societal change as well as age and developmental differences.
- Explore proxy reporting to determine accuracy and stability across type of proxy reporter (e.g., parent, translator, surveyor, clinician), the subject, and the setting.
- Develop constructs to identify intersex persons in research, clinical, public, and policy settings.
- Detail how the perception of consequences impacts responses (e.g., impact of culture and racial identity; perceived discrimination and mode of collection; effects on providers and interviewers).
- Identify ways to promote and maintain interoperability of SGM data across health care systems and platforms (e.g., EHRs).
- Develop SGM measures that consider varying uses (clinical, research, or survey). Standardize these measures and include in routine population surveys regardless of setting, as feasible; include measures of DSD/intersex.
- Study the impact on response rates and accuracy of placement and order of questions; assess impact of data collection mode as well.
- Determine how to collect, measure, and analyze the impact of perceived (by others) vs. self-identified SGM status.
- Develop measures to identify asexual people using survey-based approaches in varying contexts (general population, SGM populations, and in clinical settings).

Additional discussion focused primarily on the following areas:

- **Assessment modality:** Who is asking the questions and how those questions are being asked are critical; the person collecting data needs training and a framework, and the person being asked the questions needs to be comfortable; data collection settings can affect collection rates, but new methods of data collection, such as answering questions on a tablet, can increase responses; those collecting data need to be trained to explicitly ask questions about SGM status rather than assuming the answers; some surveys might assume gender, or use sex-segregated questions, which would negatively affect responses from SGM populations and, in the clinical setting, the EHR may prepopulate certain fields based on sex; more inclusive physiological and social questions should be determined.

- **DSD/Intersex concerns:** A wide range of medical conditions with some specific and overlapping needs have been classified under the same umbrella as SGM status; the community and subcommunities must be conceptualized to appropriately identify whether conditions apply to someone under that umbrella, and researchers need to know the relevant language to be able to recruit the populations for whom research will be relevant; an ongoing issue is whether the intersex community is well represented under the LGBTQ2S (LGBTQ and two-spirit)/SGM umbrella; the research trajectory is different, and it is important to be mindful of the capacity needed to serve every community.

- **Inclusivity:** The terminology used in records of current studies may not reflect changing standards of acceptability; the use of specific terms in funding opportunities informs applicants that it is safe to apply; increased cultural competency in the funding sphere can increase awareness of appropriate ways to encourage SGM-related research; the number of people identifying in gender-nonconforming ways is increasing, and their identification may not always match their social presentation of gender; because the language involved in describing SGM status changes, multidimensional measures may have to be used and combined differently over time or in different situations or studies; researchers need to understand whether they are collecting a personal identity label or a community identification.

- **Medical staff considerations:** Data collection methods other than those executed by clinicians, including collection by front-line staff and disclosure from home in advance of the appointment, need to be studied; standard blood value ranges for hormones and other measures need to be considered in the context of SGM status and may not be applicable to SGM patients.

- **Expansion of identities:** It is important to include a separate question to measure asexuality given the limited amount of research available; additional response categories, such as queer or pansexual, could be implemented in surveys; negative response categories to questions of sexual orientation are important, and respondents who do not understand the question, actively choose not to respond, or do not have a sexual orientation need to be better understood; there is a need to better understand the increased use of the "something else" response category when asked about sexual orientation.

RESEARCH OPPORTUNITIES IDENTIFIED:

Measurement of Related Constructs

The research opportunities highlighted below were considered by the workshop participants to be the areas of greatest need for better understanding how to measure related concepts within SGM populations. Discussion focused on stigma at various levels, the coming out or disclosure process, family relationships, and cultural competence and humility in the health care and research settings, among others. The following is not an exhaustive list of research questions to be explored.

- Develop standardized measurement of SGM-related constructs that are valid, reliable, and reproducible across groups and over time (historically and developmentally).

  - Determine contexts in which standardized measurements are not advisable or possible
  - Develop tailored measurements (e.g., age cohort, ethnoracial identity) for different SGM populations of invariant constructs (e.g., stigma consciousness, disclosure of SGM status)
  - Determine which constructs are core or invariant

- Identify and assess multiple levels of stigma and forms of discrimination (and their measures).

  - Consider change over time or with intervention
  - Identify key pathways (e.g., norms, community climate, enacted stigma, internalized stigma)
  - Research interplay of multiple stigmas (e.g., related to intersectionality by race/ethnicity, gender expression and gender identity, socioeconomic position, immigrant status, and more)

- Assess cultural and linguistic competence with SGM populations at the health care system (e.g., best practices) and provider levels.

  - Determine how to measure change over time or in response to an intervention
  - Study implicit bias among providers; explore the impact of competence on patient outcomes

- Define and measure the cultural competence of researchers focusing on SGM populations, considering the following:

  - Heterogeneity of SGM populations
  - Sensitivity to SGM populations
  - Special considerations of DSD/intersex populations
  - Theory and community relevance of hypothesis and research questions

- Identify existing measures of social relationships (e.g., intimate, romantic, caregiver-child, family, and peers); determine if the quality and characteristics are valid and reliable for SGM populations.

  - Determine if new measures of social relationships are needed (e.g., chosen families)

- Determine the best measures of parental decision-making regarding pre-pubescent children's gender identity, gender expression, and intersex conditions. Also, identify ways to assess cultural, psychological, and child-specific factors that influence parental decision-making.

- Identify and assess sources of trauma and related responses observed in diverse SGM populations.
  - Levels of trauma: individual, community, historical
  - Consider general trauma and SGM-specific trauma

- Identify and assess discriminatory beliefs and behaviors toward SGM populations and changes in beliefs and behaviors over time or in response to interventions. This may include how the media portrays SGM communities and how those portrayals reinforce or negate discriminatory beliefs and behaviors.

Additional discussion focused primarily on the following areas:

- **DSD/intersex:** Consider whether some questions reflect clinical populations with DSD, particularly regarding the use of the term "intersex"; the agreed-upon language by the medical community may not match the language used within the community; preventing harm is the most important consideration; research opportunities should be structured in a way that makes the patient population feel listened to, even when communities may disagree on the language.

- **Group inclusion:** Relationships between SGM individuals and their cultures must be addressed to meet the health needs of both individuals and communities; the definitions of "family" and "relationships" could be expanded to prevent the focus on relationships in SGM populations from becoming too monogamy-normative; the diversity of relationships present in the SGM community can affect both risk and resilience; medical conditions frequently discussed within traditional gender constructs, such as infertility or body image, are described with definitions that often exclude SGM populations; existing measures widely used in some fields need to be made more inclusive to avoid losing SGM individuals; questions also should address SGM individuals who are foreign-born or whose culture is affected by immigration, via the immigration experience and acculturation regarding gender and identity norms.

- **Intersectionality:** The dimensions of intersectionality should be defined and more explicitly stated in the research priority opportunities; constructs relevant to individuals with cognitive and physical disabilities and the incarcerated community should be considered; constructs that measure intersectional experiences are critical to ensure that measures are valid across multiple data sets.

- **Life course:** There is a need to consider issues that may affect older adults, such as a change in housing situation or experiences of victimization that differ from those of younger generations; existing measures need to be modified to be relevant to SGM-specific subgroups and generational groups within SGM populations; the fluidity of identity can change throughout the life course, although it often is assumed to be more likely in younger individuals.

- **Stigma:** More innovation is needed related to SGM-specific key pathways linking stigma to adverse effects; key pathways may be psychological or physiological, both of which require further investigation, or may not fit either category, such as denial of resources.

- **Trauma:** When dealing with medical trauma, such as that experienced by intersex individuals, individual trauma might need to be included more explicitly; trauma response often includes resilience, coping, and growth measures, and these counter-constructs are not well-represented in research opportunities; the SGM community often must adapt to survive, and positive aspects of this adaptability should be examined more closely.

RESEARCH OPPORTUNITIES IDENTIFIED:

Sampling

The research opportunities highlighted below were considered by the workshop participants to be the areas of greatest need for better understanding how to best sample SGM populations. Discussion focused on comparison of sampling methods, the innovation of new methods, harmonizing data sets, proxy measures, and new recruitment techniques. The following is not an exhaustive list of research questions to be explored.

- Compare sampling methods for each of the following:
  - Enrollment
  - Representativeness
  - Response biases
  - Rates of health outcomes
  - Limitations of each method

- Innovate new SGM sampling methods in the following regards:
  - Innovation of novel methods
  - Application of methods from other areas
  - Capitalize on lessons learned from men who have sex with men (MSM) HIV research for other SGM populations

- Harmonize data from existing data sets and ongoing studies to increase power for small populations
  - Address integrated data analyses, harmonizing measures

- Assess stability vs. fluidity of SGM status over time/development
  - Research the implications for inclusion criteria

- Reference group/comparison
    - Determine who constitutes a comparison group to SGM populations
    - Explore what methods are needed to establish valid comparisons
- Inferred/proxy measurement of SGM status
    - Examine the validity of proxy reporting on family/network
    - Utilize natural language processing in medical records
- Describe current recruitment methods in the following regards:
    - Cost per enrollee
    - Best practices
    - Reach to sub-groups
    - Inclusion criteria
- Study process and implementation of sexual orientation and gender identity (SOGI) measurements
    - Address the rollout of SOGI items into health systems, response rates, complaints, etc.

Additional discussion focused primarily on the following areas:

- **Analysis:** The analysis process and potential analytic microaggressions should be examined to ensure that the method of collecting the measures is not harmful; without guidance, an analyst might choose which classifications apply to each individual in ways that align with presentation rather than identity; although dichotomies and other such defined categories often are required for data analysis, fluidity must be understood as a continuum of both orientation and identity, and nonbinary ways of considering the data must be employed; may need to ask respondents to choose a category closest to their identity; further consideration of how to provide space for identities on a continuum is needed.

- **Comparison groups:** The question being studied should determine which group is used for comparison when the appropriate comparison group is unclear and methods for sampling such a group are unknown; this challenge limits the kinds of questions that can be addressed.

- **Data collection:** Despite recent concerns about data sharing by apps and other technologies, partnership with such systems can be an important way to gather information about small populations; more research is needed on the community perspective on research partnerships with technology systems; interviewer competence affects whether participation in the data collection harms the individual; meaningful responses are possible only when questioners are comfortable talking about SGM considerations; developing internal standards regarding pooling, adding questions to federal surveys, and gathering data about the implementation of SGM measures could help separate the science from the politics.

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- **Innovation:** Fortifying the research on sampling methods for SGM populations can help justify the funding required to develop more innovative recruitment methods to reach hard-to-count populations; innovation regarding small sample sizes is needed; various small populations likely have much to learn from each other, but these groups often are siloed, and recruitment and access considerations for each group are unique.

- **Recruitment and follow-up:** Recruitment involves ascertaining the current status of past events, and follow-up revolves around tracking future status; technology conversations should consider geographical areas where technology access is different; fluidity also must be considered in terms of whether an individual whose identification changes is considered lost to follow-up.

Conclusion/Next Steps

This document summarizes the Methods and Measurement in Sexual & Gender Minority Health Research Workshop held at the NIH in April 2018. The three main topics discussed were measurement of SGM status, measurement of related constructs, and sampling. The identified research opportunities will serve as a guide to the research community and the NIH as we work to advance the field of SGM-related methods and measures.

Appendix 1

Methods and Measures in SGM-Related Health: Developing a Research Agenda

Measurement—SGM Status	Measurement—Related Constructs	Sampling Methods
• Sexual Orientation (identity, behavior, attraction) • Gender Identity (cisgender, transgender, gender nonconforming) • Disorders or Differences of Sex Development (DSD)/Intersex (medical diagnosis vs. self-identified) • Fluidity (identity across contexts) • Assessment Modality • Clinical Settings	• Stigma (structural, interpersonal, individual) • Coming Out/Disclosure Process • Family Relationships • Cultural Competence/Humility in the Health Care and Research Setting (providers, facilities, etc.)	• Probability vs. Non-Probability Sampling • Across Demographics/Sub-Populations • Small Sample Sizes

Intersectionality →

Life Span Perspective →

Culture →

Historical Context/Cohort Effects →