

**U.S. Department of Health and Human Services (HHS)
National Institutes of Health (NIH)
Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)
Sexual & Gender Minority Research Office (SGMRO)**

Sexual and Gender Minority (SGM) Health Listening Session

**Virtual
November 19, 2020
1:00 p.m. – 2:30 pm EST**

Meeting Summary

INTRODUCTION

The NIH SGMRO convened its second annual SGM Health Research Listening Session on November 19, 2020—its first virtual session. Eleven representatives from SGM-focused health and health advocacy organizations were in attendance. The primary objective was to gather comments, concerns, and suggestions about SGM-related health research and related activities at the NIH from community stakeholders. The major goal was for NIH leaders and staff to hear what is on the community stakeholders' minds regarding SGM-related research. This document summarizes the session's discussion and does not represent official positions of the NIH or any other government agency.

PARTICIPANTS AND STRUCTURE OF THE LISTENING SESSION

The 2020 SGM health research and health advocacy groups (see Appendix 1 for the list of community stakeholder participants) were selected based on their many and various organizational missions and initiatives to ensure that a diversity of perspectives was represented. NIH's commitment to SGM health research in terms of programs, initiatives, and funding was conveyed by staff (directors, deputy directors, program officials, and advisors) from several NIH Institutes, Centers, and Offices (ICOs), namely the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Institute on Drug Abuse, National Institute of Mental Health, National Institute on Minority Health and Health Disparities, Office of AIDS Research, and Scientific Workforce Diversity Office. Participants shared their comments and concerns with NIH leadership and representatives of these six ICOs (see Appendix 2 for the list of NIH participants).

These SGMRO-hosted listening sessions provide unique opportunities for leaders in SGM health and advocacy to voice concerns and bring attention to challenges in and barriers to SGM health research. The discussion was structured so that each invited participant was allotted 5 minutes to speak. The session was open to the public via telephone or video, and a video recording and transcript are available on the [SGMRO website](#). Public comment was accepted after the conclusion of the listening session and was collected via email at SGMRO@nih.gov.

MAJOR THEMES FROM THE LISTENING SESSION

Numerous themes and topics for consideration emerged from the session:

- **Scientific Gap Areas in SGM Health Research**
 - ***SGM Health Equality and Inclusion***
 - Implement measures to recruit SGM participants in clinical trials, continue to promote nondiscrimination in health care, and ensure requirements for demographic variable collection to make certain that the full breadth of diversity is accurately captured.
 - Address population-specific needs, especially those of nonbinary people, people with disabilities, and people of color.
 - Expand inclusion in health policies and programs.
 - Address education and training at all levels of health.
 - ***Bisexual-Specific***
 - Consider ways to provide places (i.e., environments and dedicated-staffed organizations) that meet the community's unique and pressing needs, so that the rates of physical, mental, social, and sexual abuse are markedly reduced.
 - Address urgent, systemic needs (e.g., tools and resources) to achieve full lesbian, gay, bisexual, transgender, and queer (LGBTQ) status.
 - Address the deep-rooted misconceptions (e.g., disloyalty, greed, or hypersexuality) that often are used as criteria for exclusion.
 - ***Transgender-Specific***
 - Support more research to better understand and address the mental health needs and trauma experienced.
 - ***Black Lesbian-Specific***
 - Increase focus on the unique health concerns of Black lesbians and address the dearth of research involving these populations.
 - ***Intersex-Specific***
 - Promote ending medically unnecessary surgeries on intersex children and create healthy alternatives in health care for intersex children and adults.
 - Encourage SGM community partners to take a stand in creating comprehensive health care for intersex youth.
 - Incorporate newer intersex research and follow-up beyond the outcomes of post-surgical procedures that incorrectly assign gender identity based on dated research.
 - ***Two-Spirit (2S)-Specific***
 - Consider listing 2S first in acronym “2SLGBTQI+ and non-heterosexual” when addressing research.
 - Adopt approaches focusing on changing the system regarding the language and colonial structures and framing messages. Make changes to the systems of homophobia, settler colonialism, transphobia, and racism to have a positive impact and redress the historical wrongs that play out in policies and programs.

- **SGM Data Collection**

- Collect data (1) on how the community influences isolation for Black lesbians, (2) on how social support systems foster resilience, and (3) to develop interventions and evaluate the effectiveness of innovative holistic care models based within this community.
- Improve the collection of sexual orientation and racial identity data, which should be universally incorporated into electronic health records and other databases and are essential for building the evidence base to understand disparities for those at the intersection of marginalizations regarding racial and sexual identities.
- Develop ways to analyze data for populations who are Black, Indigenous, or people of color (BIPOC).
- Improve sexual orientation and gender identity data collection across all age groups, especially for those age 13 years and younger, and make these data disaggregated and readily available to the public in a manner that provides the necessary granularity.
- Collect new data on which intersex surgeries are critical and medically necessary, and promote publishing data on lesser-known studies investigating intersex surgeries to better inform the medical community of the high rates of depression and suicide precipitated by these types of procedures.
- Improve data collection for LGBTQ people in nonclinical projects, such as national population surveys, and ensure 2S data collection within various research projects using recent approaches defined by this group.

- **Fund SGM Health Research**

- Increase funding for SGM research in general and, in particular, earmark funding for bisexual+, intersex, and 2S research that offsets the generous support of volunteers and nonprofit organizations and matches or exceeds the investments of NIH counterparts in other countries (e.g., Canada).
- Fund U.S.-based research that is driven by intersex people and activists to (1) reduce the significant mental health issues that affect younger individuals between ages 18 and 39 and (2) alleviate marginalization, particularly by pediatric urologists, in the intersex population.
- Support funding to collect data in new cohorts (e.g., Black lesbians) to develop and test innovative holistic care model-based interventions and evaluate the effectiveness of these models within the SGM community, with links to culturally competent facility-based services.
- Consider funding programs addressing cancer health disparities that incorporate training and counseling of sexual minority women in engagement, retention in care, and support services.
- Fund community-level interventions to better understand disparities in social determinants of health.
- Support funding for health organization services to the intersex community, thereby ensuring quality and competent care across the lifespan of these individuals.

- **Expand SGM Health Research Across SGM Populations**

- Support research that is comprehensive, inclusive, and intersectional, and expand research to other areas, including best practices in primary care and interventions.

- Disaggregate data to better understand and address health disparities affecting specific SGM subpopulations.
- Focus on interventions addressing reproductive health and family planning needs and research on thriving, flourishing, and triumphing to reframe the way the public thinks about and understands SGM groups.
- Expand the NIH research portfolio to include underrepresented SGM communities living in rural areas and other less accessible parts of the country, particularly to understand the impact of public health crises, such as COVID-19, and to inform interventions.
- Develop community-grounded, community-driven, holistic, and critically sound approaches to health disparities research on aging Black and Asian lesbians and Black queer, same-gender-loving bisexual, transgender, and gay people.
- Improve research study design and knowledge translation and dissemination by using appropriate control groups for comparison with the various SGM populations, especially in a manner that promotes better understanding of gender-diverse youth and transgender and gender non-binary people.
- Consider research that supports medical guidelines and the dissemination of evidence-based guidelines.
- Include all SGM populations not currently identified (e.g., 2S) in the research question about sex- and gender-based analysis contained in NIH research proposals.
- **The Sexual & Gender Minority Research Office**
 - Continue to increase the SGM research portfolio, particularly in support of initiatives addressing stigma as a key component to understanding development and resilience.
 - Consider supporting research that addresses weight-based bias or sizeism as one axis of oppression to examine, especially among cis lesbian and bisexual women.
 - Encourage investigators to engage in community-based research focusing on the lives and well-being of sex workers beyond a pure HIV-prevention scope, emphasizing the experiences of victimization, police violence, and criminalization.
 - Support programs that examine the longitudinal health risks of gender-affirming therapies on transgender and gender-diverse people across the NIH ICOs.
 - Encourage investigators to evaluate additional interventions aimed at improving the social and economic conditions for Black sexual minority men as one way to address the HIV epidemic, thus moving beyond solely behavioral and peer group changes.
 - Continue support for early-stage LGBTQ investigators of color and trans-identified researchers to increase pathways for future NIH research, and consider establishing a 2S support program for junior investigators.
 - Increase grant initiatives that establish larger cohorts or biorepository studies in the United States to increase research collaboration and allow connection of biomarkers to assess long-term health risks of gender-affirming therapies.
 - Support additional studies in BIPOC transgender communities to better understand their unique health concerns and needs.

CONTRIBUTIONS FROM THE PUBLIC POST-LISTENING SESSION

The public was provided an opportunity to share comments, questions, and feedback with the SGMRO via email after the listening session. Two individuals/organizations provided feedback. The main topics identified were—

- **SGM Health Research**
 - Hormone Replacement Therapy (HRT)
 - Investigate the long-term health effects of HRT in trans people.
 - Research resiliency factors in trans people and focus on how HRT and social acceptance decrease suicidality and depression in trans people.
 - Consult trans and gender non-conforming (GNC) researchers at all phases of research studies, such as planning, initiation, execution, and interpretation. Consider also seeking trans and GNC community leaders as consultants.
 - Medical Detransition
 - Develop best practices for medical detransition for the growing number of trans-identifying young people who come to regret their decision and wish to restore their physical and mental health.
 - Develop best practices for mental health assessment, including an understanding of co-morbid mental health issues, of young people with gender dysphoria.
- **The Sexual & Gender Minority Research Office**
 - Publish a “best practices” article on language usage guidance.
 - Review current funding to identify research using puberty blockers on minors to identify possible ethical violations of informed consent.

CONCLUSION

The NIH appreciates all who participated in the virtual meeting. On September 17, 2020, SGMRO released the [*NIH Strategic Plan to Advance Research on the Health and Well-being of Sexual & Gender Minorities for Fiscal Years 2021–2025*](#). To track progress on achieving the strategic plan goals, the SGMRO will seek feedback on an annual basis related to SGM health, research, and related activities at the NIH from community stakeholders and the public.

Appendix 1

SGM Health Research and Health Advocacy Participants

Bisexual Resource Center	Alexandra Bolles
GLMA: Health Professionals Advancing LGBTQ Equality	Scott Nass, M.D., M.P.A., FAAFP, AAHIVS
Howard Brown Health	David Ernesto Munar
Intersex Justice Project	Sean Saifa Wall
Los Angeles LGBT Center	Chloe Opalo
ZAMI NOBLA-National Association of Black Lesbians on Aging	Mary Anne Adams, M.S.W.
National Black Justice Coalition	Kia Darling-Hammond, Ph.D.
The Houston Intersex Society	Koomah
Two-Spirit Activist and American Indian/Alaska Native Community Members	Harlan Pruden Jessy Dame, R.N.
Williams Institute	Bianca D.M. Wilson, Ph.D.
World Professional Association for Transgender Health	Vin Tangpricha, M.D., Ph.D.

Appendix 2

NIH Institutes, Centers, and Offices Participants

Eunice Kennedy Shriver National Institute of Child Health
and Human Development

Alison Cernich, Ph.D.

National Institute on Drug Abuse

Wilson Compton, M.D., M.P.E

National Institute of Mental Health

Joshua Gordon, M.D., Ph.D.

National Institute on Minority Health and Health Disparities

Jennifer Alvidrez, Ph.D.

Office of AIDS Research

Maureen Goodenow, Ph.D.

Scientific Workforce Diversity Office

Charlene Le Fauve, Ph.D.

Sexual & Gender Minority Research Office

Karen Parker, Ph.D., M.S.W.