

Sexual & Gender Minority Research Office

FISCAL YEAR

Annual Report

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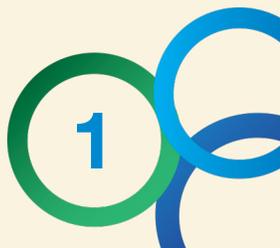
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Introduction

The Sexual & Gender Minority Research Office (SGMRO) at the National Institutes of Health (NIH) was established in 2015 to coordinate sexual and gender minority (SGM)-related research and other activities by working directly with the NIH Institutes, Centers, and Offices (ICOs). Each year, the Office publishes a portfolio analysis that describes SGM-related research funded by the NIH in a given fiscal year. In addition, the SGMRO presents a representative sample of research-related activities and initiatives from across the agency in an Annual Report. This report illustrates the breadth of SGM-relevant work being conducted across the ICOs. The report is organized around the four goal areas of NIH's [FY 2016–2020 Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities](#).





Goal 1

Expand the Knowledge Base
of SGM Health and Well-Being
Through NIH-Supported Research

Funding Opportunity Announcements

The NIH continued to fund SGM-related research through the Funding Opportunity Announcement (FOA), [The Health of Sexual and Gender Minority Populations](#). This FOA supported several activity codes, including the R01 (PA-18-037), R21 (PA-18-040), R03 (PA-18-054), and R15 (PA-18-210). Ten ICOs participated in this funding solicitation. This FOA expired in September 2018.

Fiscal Year (FY) 2018 marked the first receipt date under the R01 FOA [Research on the Health of Transgender and Gender Nonconforming Populations \(PA-18-729\)](#) and its R21 companion (PA-18-728). Fourteen ICOs are participating in this announcement.

For the third year, the SGMRO released the [Administrative Supplements for Research on Sexual and Gender Minority Populations FOA \(PA-18-713\)](#). The SGMRO received 20 responsive applications across 5 NIH Institutes in FY 2018. NIH funded 15 administrative supplements under this announcement. Several Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) Offices are providing additional funding, including the Office of AIDS Research (OAR), the Office of Behavioral and Social Sciences Research (OBSSR), the Office of Disease Prevention (ODP), and the Office of Research on Women's Health (ORWH). The 15 confirmed applications total \$1,459,016. This is an increase of more than 33 percent from FY 2017 administrative supplement funding, which totaled \$1,091,451.



In addition, several Institutes and Centers issued or extended FOAs that solicit SGM-relevant research in FY 2018. The following list represents a sample of funding announcements that either explicitly, or implicitly, call for studies that include at least one sexual or gender minority population:

- [Addressing the Challenges of the Opioid Epidemic in Minority Health and Health Disparities Research in the U.S.](#)
- [Detecting and Preventing Suicide Behavior, Ideation and Self-Harm in Youth in Contact with the Juvenile Justice System](#)
- [Geriatrics and Clinical Gerontology Research to Address Health Disparities in the U.S.](#)
- [Health Disparities and Alzheimer's Disease](#)
- [HIV/AIDS High Priority Drug Abuse Research](#)
- [Implementing the Most Successful Interventions to Improve HIV/AIDS Outcomes in U.S. Communities](#)
- [Increasing Uptake of Evidence-Based Screening in Diverse Adult Populations](#)
- [Innovations for Healthy Living - Improving Minority Health and Eliminating Health Disparities](#)
- [Mechanisms of Disparities for HIV-Related Co-morbidities in Health Disparity Populations](#)
- [Mobile and Connected Health Interventions to Improve Care Continuum and Health Outcomes among Youth with HIV](#)
- [Research on the Health of Women of Understudied, Underrepresented and Underreported \(U3\) Populations – An ORWH FY18 Administrative Supplement](#)
- [Reducing Stigma to Improve HIV/AIDS Prevention, Treatment and Care in Low and Middle-Income Countries](#)
- [Research on Pre-Exposure Prophylaxis \(PrEP\) to Prevent HIV in Health Disparity Populations](#)

Data Collection

In January 2018, the NIH Clinical Center began collecting the gender identity of all NIH research participants. Trainings about SGM-inclusive health care and new data collection requirements were provided to front-line and clinical staff prior to the commencement of data collection. Additional trainings are being developed and will be incorporated into mandatory training requirements for all Clinical Center staff. Additionally, after receiving feedback from transgender research participants, the Clinical Center removed the sex marker from patient wristbands to establish a more affirming environment for transgender and gender nonconforming patients.

The SGMRO Director and colleagues from the Clinical Center were recognized for their work in implementing the collection of the gender identity of NIH intramural research participants. This group award was presented at the NIH Clinical Center CEO Awards Ceremony.

In early FY 2018, the SGMRO provided funding for the sexual identity question and high-risk behavior module in the [General Social Survey](#) (GSS). The GSS, a household-based survey used to monitor behaviors, experiences, attitudes, and societal structure in the United States, is conducted in both English and Spanish and has a response rate of more than 70 percent. Typically funded by the Centers for Disease Control and Prevention, data have been collected during several waves. The SGMRO provided funding to ensure that a gap in data collection would not occur.

In FY 2018, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) continued to support the [U.S. Transgender Population Health Survey](#), the first national probability sample of transgender individuals in the United States. The survey will provide a more accurate and detailed picture of the issues faced by transgender people, and is also supported by the OBSSR and the ORWH.

Other SGM-Related Activities

An *ad hoc* steering committee of the National Academy of Medicine organized a public workshop co-sponsored by the NIH to discuss issues of conducting research on small population subgroups that are underrepresented in health research. There continue to be subpopulations that are often difficult to include in research studies because of their small size, dispersion, and/or accessibility. Workshop attendees considered ways of addressing the challenges of research and interventions with small population groups, including alternative study designs and innovative methodological and statistical techniques. SGM populations were included in these workshop discussions. Funding for the workshop spanned several NIH ICOs, including the National Cancer Institute (NCI), the National Institute on Minority Health and Health Disparities (NIMHD), and OBSSR.

In April 2018, the SGMRO hosted a workshop entitled *Methods and Measurement in Sexual & Gender Minority Health Research*. One of the workshop's overarching goals was to balance community and scientific perspectives in identifying the methods, measurement gaps, and needs in SGM research. This initiative is one way in which the NIH is addressing SGM-related provisions in the [21st Century Cures Act](#), which directs the NIH to encourage efforts to improve research related to the health of SGM populations. The workshop focused on three

areas: (1) sampling methods, (2) measurement of SGM status, and (3) measurement of related constructs. A [summary](#) of the workshop is posted on the SGMRO website.

Also in April 2018, the National Academy of Medicine held a planning meeting on the demography of sexual and gender minorities. Topics included: demography and identity; social positioning and well-being across the life course; health disparities, structural stigma, policy impacts and approaches; and measurement needs. Funding was provided by the SGMRO, NIMHD, and the National Institute on Aging (NIA).

In June 2018, the National Institute on Alcohol Abuse and Alcoholism (NIAAA) held a 1-day workshop at the NIH that featured presentations from all NIAAA-supported grantees conducting SGM-related research. The meeting was intended to assess recent progress and examine in greater depth the Institute's research needs in addressing problem drinking issues among SGM populations. The discussions and suggestions that emerged from this meeting are likely to shape NIAAA's—and Federal partners'—thinking regarding NIAAA's ongoing strategic planning process. This research program has experienced rapid growth at NIAAA in recent years. The meeting brought together researchers involved in epidemiological and etiological work, as well as those developing preventive interventions for problem drinking among SGM populations. The meeting discussions identified barriers to conducting research in this area and produced strategies to successfully overcome them, while also fostering networking among workshop participants and meeting observers that may give rise to subsequent research collaborations.

In FY 2018, the National Institute on Drug Abuse (NIDA) created a [website](#) to solicit research in areas of high scientific priority. Current areas of special and/or continuing interest include understanding and preventing drug use, abuse, and addiction in diverse communities, including SGM populations.



Goal 2

Remove Barriers to Planning, Conducting, and Reporting NIH-Supported Research About SGM Health and Well-Being

Outreach, Education, and Coordination

In FY 2018, the SGMRO Director began serving on a number of NIH-wide committees to increase understanding about SGM-related research and the intersections between SGM research and ICO missions and priorities, and to ensure that SGM-related concerns are incorporated into work across the NIH. Within the NIH, new committees include the *All of Us* Research Program Trans-NIH Liaisons Coordinating Team, the Office of Research on Women's Health Strategic Planning Team, and the Trans-NIH Minority Health and Health Disparities Strategic Planning Committee.

The SGMRO Director also is actively involved in several committees that span the Department of Health and Human Services (HHS) and other Governmental Departments. For example, the Director serves on the Healthy People 2030 LGBT subcommittee, which works to ensure integration of LGBT-related objectives in Healthy People 2030. In addition, the Director is co-chair of the youth subcommittee of the Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity (SOGI) in Federal Surveys. This subcommittee, which also includes NICHD staff, is exploring the unique challenges faced in measuring SOGI constructs in youth.

In FY 2018, the SGMRO coordinated a [Safe Zone](#) training open to all staff within the DPCPSI in the NIH Office of the Director (OD). The training was well received by colleagues throughout the Division. Safe Zone seeks to promote NIH community awareness and education about the needs and concerns of people who identify as sexual and gender minorities. Safe Zone encourages everyone to show support for—and actively affirm—SGM colleagues and friends.



In FY 2018, *All of Us* conducted multiple activities to inform SGM communities about this research program and to support and improve SGM engagement and enrollment. In partnership with the San Francisco General Hospital, *All of Us* established a national network of 24 organizations in 12 states to educate SGM individuals about joining the program. The program developed SGM cultural competency and humility training for the *All of Us* consortium. As of September 30, 2018, *All of Us* had enrolled 6,484 self-identified SGM core participants out of 64,107 total core participants. This accounts for 10.1 percent of the *All of Us* core participants.

The *All of Us* program established the SGM Technical Assistance Center to support health care provider organizations enrolling *All of Us* patients and the SGM Engagement Network's Participant Advisory Committee. *All of Us* program staff conducted outreach and awareness events, including at LGBT-focused conferences, and recruited and trained LGBT influencers to disseminate *All of Us*-approved collaterals and messaging in presentations and social media. Staff also published an [article](#) in the *Journal of Translational Medicine* that discussed strategies for engaging SGM populations.

At the 2018 Annual Meeting of the Society of Prevention Research, which is supported through several NIH ICOs, including NIDA, a brown bag event was held to discuss the current state of prevention science for LGBT populations. The group examined the current state of the literature and how prevention science research and implementation strategies could best help to alleviate LGBT health disparities. This meeting served as the foundation for a collaborative, interdisciplinary proposal for a special section of the journal *Prevention Science* focused on LGBT health.

In May 2018, the Director of the National Institute of Mental Health (NIMH) Division of AIDS Research presented a [concept](#) entitled "Promoting Reductions in Intersectional StigMa (PRISM) to Improve the HIV Prevention Continuum" at the National Advisory Mental Health Council (NAMHC) meeting. The concept includes a clear focus on multiple stigmatized identities related to sexual orientation, gender, and race among people at substantial risk of acquiring HIV.

In June 2018, NIMH also led a symposium entitled Reducing Intersectional Stigma to Improve the HIV Prevention Continuum at the 13th International Conference on HIV Treatment and Prevention Adherence. The session focused on understanding how multiple stigmatized identities related to sexual orientation, gender, and race interact among people who are at high risk of acquiring HIV.

In July 2018, the SGMRO Director participated in a congressional briefing focused on transgender health sponsored by the Endocrine Society. The briefing provided an opportunity to highlight the work of the SGMRO with congressional staff and other interested parties.



Technical Assistance to Principal Investigators

The SGMRO Director continued to provide technical assistance to NIH staff and the extramural research community. Principal Investigators were connected to Program Directors across the agency.

Throughout FY 2018, extramural scientific project officers at several ICOs provided technical assistance to potential applicants interested in submitting applications to conduct research among SGM populations, guiding applicants in how best to align their research aims with ICO priorities across the spectrum of basic science, epidemiology, prevention, and treatment research.

In September 2018, NIMHD staff conducted a technical assistance webinar for potential applicants to the Extramural Loan Repayment Program for Health Disparities Research, which provides loan repayment for investigators engaging in health research in SGM and other disparities populations.

Presentations

Throughout FY 2018, the SGMRO Director made presentations to both the NIH community and outside institutions. Below is a list of the presentations that were made to raise awareness about SGM-related work at the NIH, and to teach grantpersonship to researchers and scholars interested in applying for NIH funding.

Presentations Made at NIH/HHS

- Amgen Scholars at NIH
- HHS, Office of Global Affairs
- National Institute of Allergy and Infectious Diseases
- National Institute of Diabetes and Digestive and Kidney Diseases
- National Institute of Mental Health
- National Institute of Nursing Research
- National Institute on Minority Health and Health Disparities, Health Disparities Research Institute

Presentations Made in the Extramural Community

- American Association for the Advancement of Science (Washington, DC)
- Building the Next Generation of Academic Physicians (New York, NY)
- Building the Next Generation of Academic Physicians (Webinar)
- Congressional Briefing on Transgender Health (Washington, DC)
- Endocrine Society's 100th Annual Meeting (Chicago, IL)

- Hood College (Frederick, MD)
- Maryland Association of Health Care Executives (Bethesda, MD)
- National Transgender Health Summit (Oakland, CA)
- Perelman School of Medicine, University of Pennsylvania (Philadelphia, PA)
- Robert Wood Johnson Health Disparities Fellows (Washington, DC)
- The Institute for Patient-Centered Initiatives and Health Equity at the George Washington Cancer Center (Washington, DC)

Other SGM-Related Activities

In FY 2018, the Office of Intramural Training and Education (OITE) continued to coordinate the NIH LGBT Friends and Fellows (LGBT-FF) group. The LGBT-FF helps its members thrive in their professional and personal lives by addressing issues unique to the LGBT community. LGBT-FF organizes seminars and workshops to educate the general public on LGBT issues, provides professional development opportunities, and offers social and networking events to develop professional and personal networks. LGBT-FF is open to straight and LGBT-identified NIH fellows, from postdoctoral scholars to graduate students, postbaccalaureates, and summer interns.

The LGBT-FF hosted a workshop in March 2018 on embracing identities of self and others. This workshop explored the landscape of sexual orientation and gender identity with an opportunity for participants to reflect on their own identities while also identifying ways to welcome and support the identity of others. The LGBT-FF group also hosted a presentation by a representative from the Human Rights Campaign that focused on progress to date in LGBT legal rights.

OITE also sponsors the NIH Academy, which offers trainees the opportunity to learn about health disparities, enhance their knowledge of disparities in health outcomes, and investigate what is being done to address disparities. The NIH Academy trains future researchers and physician-scientists to actively engage in promoting a society in which all people live healthy lives and have equal access to health care. In FY 2018, OITE hosted two Academy seminars that included SGM-related content.

NIH Academy Seminars

Comprehensive Health Reform in America: Advancing Health Equity—November 2017

Understanding Psychosocial, Behavioral, and Substance Use Correlates of STI and HIV Risk among Men Who Have Sex with Men and Men Who Have Sex with Men and Women—April 2018

NIH Academy Diversity Course

Diversity in a Multicultural Society Part 3 Sex, Gender, & Sexual Orientation—January 2018



Goal 3

Strengthen the Community of Researchers and Scholars Who Conduct Research Relevant to SGM Health and Well-Being

Mentoring Researchers

The SGMRO's inaugural Sexual & Gender Minority Regional Workshop was held on May 12, 2018, in Boston, Massachusetts. Goals of the Regional Workshop included: increasing understanding of the NIH structure and processes; developing mentoring relationships within the extramural research community; enhancing capacity to conduct SGM research; and providing researchers with the opportunity to interact with NIH staff, community members, and established researchers in SGM health. Agenda highlights included roundtable discussions about participant research ideas and networking opportunities. Representatives from NIMHD, NIMH, NICHD, NIDA, the National Institute of Allergy and Infectious Diseases (NIAID), and the Center for Scientific Review (CSR) participated in the Regional Workshop. Feedback received from participants was overwhelmingly positive. The SGMRO is planning two Regional Workshops in FY 2019.

In FY 2018, the SGMRO announced its inaugural Investigator Award Program. The NIH Investigator Award Program in SGM Health Research was developed to recognize Early Stage Investigators who have made substantial, outstanding research contributions in areas related to SGM health and who are poised to become future leaders or already are leading the field of SGM health research. Awardees were invited to the NIH to promote their research and were presented with nonmonetary awards.

For the third year, the SGMRO co-sponsored the NIMHD Health Disparities Research Institute (HDRI) at the NIH. The HDRI supports the research career development of promising minority health and health disparities research scientists early in their careers and stimulates research in the disciplines supported by health disparities science. In addition to a monetary contribution, the SGMRO Director made a presentation to the scholars on SGM-related activities at the NIH.

In FY 2018, NICHD's Division of Intramural Research (DIR) continued to promote the health of intersex patients and individuals with differences in sexual development (DSD) through fellowship training programs in pediatric endocrinology and medical genetics. DIR also remains involved in a national consortium of endocrine training programs with related clinical programs that help to advance SGM research and training.

In July 2018, NIMHD, NICHD, and staff from the NIH OD participated in a panel discussion on SGM and health disparities as part of the Amgen Scholars Program at the NIH, which brings undergraduate students to the NIH for a summer to gain practical laboratory experience and mentorship from NIH scientists in preparation for graduate education and scientific research careers.

Other SGM-Related Activities

The NCI's Division of Cancer Control and Population Sciences hosted the Training Institute for Dissemination and Implementation Research in Cancer to provide participants with a foundation in conducting dissemination and implementation research with a focus on cancer. The Institute included a 4-month-long online course and a 2-day in-person training in Bethesda, Maryland. The SGMRO Director served as a faculty mentor for a participant conducting SGM-related dissemination and implementation research.

An NIMH program director delivered a webinar on November 7, 2017, entitled Strategies and Tools to Maximize PrEP Adherence in MSM. The webinar was organized by the HIV/AIDS Network Coordination (HANC) Youth Prevention Research Working Group.

In April 2018, another NIMH program director helped lead a symposium entitled Extending the Research of Longitudinal Stigma Research to Advance HIV Treatment and Care at the Society for Behavioral Medicine's Annual Meeting. The session included a clear focus on multiple stigmatized identities related to sexual orientation, gender, and race among people living with HIV.

Also in April 2018, an NIA program director participated in a panel discussion and presented NIA's SGM programmatic interests at The Resource Centers for Minority Aging Research (RCMAR) Annual Investigators Meeting.

The NICHD was represented at the LGBTQ in Leadership Panel at Johns Hopkins University, which included discussions about the career paths and experiences of SGM individuals in science, technology, engineering, and medicine (STEM), as well as recommendations for success.



Goal 4

Evaluate Progress on Advancing SGM Research

The SGMRO compiled data on SGM research from FY 2017 using the [NIH RePORTER](#). The 379 projects that comprise the FY 2017 NIH SGM portfolio (up from 334 SGM projects in FY 2016) were identified using the “Sexual and Gender Minorities (SGM/LGBT*)” category in NIH’s [Research, Condition, and Disease Categorization](#) (RCDC). RCDC is a computerized process used annually to categorize NIH funding by research or disease area. The SGM/LGBT* category was added in FY 2015 to the official list of the currently reported 288 RCDC categories, so this estimate of SGM projects and spending constitutes the second report of those data. Reflecting the NIH’s inclusive approach to SGM health research, the RCDC category includes lesbian, gay, bisexual, and transgender populations, as well as many others. For example, men who have sex with men (who may not identify as gay or bisexual), two-spirit populations, and those with a DSD, sometimes described as intersex populations, are included in the NIH definition of SGM.

The RCDC process relies solely on the clarity and specificity of the text included in grant applications and uses the most up-to-date trans-NIH definitions for determining inclusion or development of categories. For these reasons, researchers viewing the RCDC project listings might agree or disagree with the categories in which their projects appear. The SGMRO works with the NIH ICOs to validate and refine the SGM fingerprint to ensure that the most accurate data are available to the public through the [NIH RePORTER](#) website. The most recent validation of these data was performed in FY 2017.

As noted in the [Strategic Plan](#), the NIH evaluates its efforts on an annual basis. In FY 2018, the SGMRO released both the [FY 2016 Portfolio Analysis](#), highlighting SGM-related research projects, and the [FY 2017 Annual Report](#), capturing other SGM-related work at the NIH.

In September 2018, the NIH Sexual & Gender Minority Research Working Group of the Council of Councils convened to evaluate NIH's progress on its SGM Research Strategic Plan. The Working Group developed recommendations across the four goal areas of the Plan. The recommendations were presented to the DPCPSI Council of Councils in January 2019 and received unanimous support. The NIH Director accepted the recommendations on behalf of the agency.

The NIH remains dedicated to the expansion of SGM-related health research, as it continues to create and promote opportunities for research and encourage SGM measurement and data collection. The agency also has made significant strides in strengthening the existing community of SGM health scholars and researchers while conducting initiatives to recruit and commend new investigators in this field. Intra-agency collaboration has been, and will continue to be, pivotal in ensuring that SGM-related concerns are being addressed in intramural and extramural research across all of the ICOs.

Since the release of the NIH SGM Research Strategic Plan (FY 2016–2020), much has been accomplished across the agency toward addressing the goals of the Plan. With the ongoing commitment and support from NIH leadership for this work, and taking into consideration the recommendations outlined by the SGM Research Working Group, the SGMRO will continue to build on the agency's considerable progress through new and robust initiatives throughout FY 2019.



National Institutes of Health
Sexual & Gender Minority Research Office