



# FY 2016 Sexual and Gender Minority Research Office

# Annual Report



National Institutes of Health  
Sexual and Gender Minority Research Office

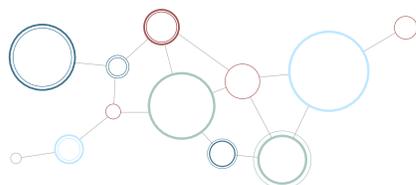


*The SGMRO coordinates sexual and gender minority (SGM)-related research and activities by working directly with NIH Institutes, Centers, and Offices (ICOs) and by providing a point of contact for stakeholders outside of the NIH.*

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## Introduction

The mission of the National Institutes of Health (NIH) is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. At the NIH, the Office of the Director (OD) is the central office responsible for setting policy for the NIH and for planning, managing, and coordinating the programs and activities of the NIH's 27 components. The Sexual and Gender Minority Research Office (SGMRO) resides within the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) in the OD.



## Sexual and Gender Minority Research Office

The SGMRO coordinates sexual and gender minority (SGM)-related research and activities by working directly with NIH Institutes, Centers, and Offices (ICOs) and by providing a point of contact for stakeholders outside of the NIH. The office was officially established in September 2015.

*Sexual and gender minority* is an umbrella phrase 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.

The NIH recognizes the dearth of research in SGM-related health and is taking steps to address this lack of knowledge. This report highlights SGM-related research advances and research-related activities at the NIH during Fiscal Year (FY) 2016. The examples in the next section illustrate the breadth of activities across the agency; this report is not intended to be an exhaustive list of all NIH SGM-related activities. Several of the items included are mapped to the four goals of the NIH SGM Research Strategic Plan. For information on the SGM-related grants funded by the NIH, a [companion document](#) provides an analysis of the FY 2015 SGM research portfolio.



## NIH SGM Research Strategic Plan

In 2015, the NIH released its first SGM Research Strategic Plan to help guide efforts to increase research and supporting activities in SGM health. The plan has four goals and 11 objectives. Several key sources were utilized in the development of the plan:

- A review of the scientific literature spanning the Lesbian, Gay, Bisexual, and Transgender (LGBT) population, outlined in the 2011 Institute of Medicine report
- An analysis of the NIH SGM research portfolio
- Multiple listening sessions with diverse audiences, including SGM health researchers and key stakeholders
- A Request for Information through which members of the public could share their thoughts, experiences, and recommendations.

Once the data were collected, NIH staff reviewed, analyzed, collated, and assembled all responses, and found that certain specific themes emerged. From these data, the NIH distilled the following research and research-related goals:

- Expand the knowledge base of SGM health and well-being through NIH-supported research
- Remove barriers to planning, conducting, and reporting NIH-supported research about SGM health and well-being
- Strengthen the community of researchers and scholars who conduct research relevant to SGM health and well-being
- Evaluate progress on advancing SGM research.

The NIH believes that these goals will provide the building blocks for future discovery, and lead to the development of additional priority goals and objectives in future years to improve our understanding of the health of SGM populations.

## GOAL 1

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

## Introduction



The expansion of the knowledge base of SGM health is critical because so little information about this topic exists, and SGM-related disparities research is in its infancy. Better methods are needed to measure the SGM population, such as basic demographic information that includes the incidence and prevalence of many diseases and conditions, as well as a foundational understanding of the health of SGM subpopulations. Despite these challenges, investigators are developing novel ways to conduct meritorious research that meaningfully captures the health conditions and needs of SGM communities. The NIH continues to promote SGM-related research; in FY 2016, several research-related activities occurred across several ICOs.

## Funding Opportunity Announcements

The NIH is working to stimulate SGM-relevant research with targeted Funding Opportunity Announcements (FOAs), as well as others that are related to SGM health and well-being. The SGMRO oversaw the issuance and award of [Administrative Supplements for Research on Sexual and Gender Minority \(SGM\) Populations](#). Fifteen NIH ICs signed on to this FOA. Awards totaling \$898,656 were made to nine grantees. The Administrative Supplement opportunity was such a success that it was reissued in FY 2017.

The [Health of Sexual and Gender Minority Populations](#), sponsored by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) with multiple co-sponsors, continued to elicit a robust response from the research community in FY 2016. This announcement was issued to encourage research in biological, clinical, behavioral, and social processes that affect the health and development of SGM populations and their families. It also supports research that leads to the development of interventions and service delivery methods to enhance our understanding of the health and development of SGM populations.

[Multidisciplinary Approaches for Developmental Research with Individuals with Disorders of Sex Development](#), sponsored by NICHD with National Cancer Institute (NCI) co-sponsorship, resulted in four new awards in FY 2016.

*The NIH continues to promote SGM-related research; in FY 2016, several research-related activities occurred across several ICOs.*

The National Institute of Mental Health (NIMH) Division of AIDS Research published the FOA, [HIV Pre-exposure Prophylaxis \(PrEP\) Implementation Science in CDC-funded Public Health Demonstration Projects](#), designed to advance HIV prevention among men-who-have-sex-with-men (MSM) and transgender individuals. These Administrative Supplements were added to an ongoing U.S. public health initiative to identify and engage MSM and transgender persons who would benefit from HIV preventive medicine (PrEP). Eight FY 2016 Administrative Supplement awards will support the development of PrEP implementation metrics and evaluation of PrEP navigation, prescribing, and adherence support activities among MSM and transgender individuals in locations that include Baltimore, Maryland; Detroit, Michigan; and Memphis, Tennessee.

Recognizing the need to improve measurement in SGM research, the Office of Behavioral and Social Sciences Research (OBSSR) included SGM-specific language in its FOA, [Methodology and Measurement in the Behavioral and Social Sciences](#).

In 2016, the National Institute on Drug Abuse (NIDA), requested research proposals for its FOA, [Seek, Test, Treat and Retain for Youth and Young Adults Living with or at High Risk for Acquiring HIV](#). Of particular interest are sexual and gender minority youth who may be at especially high risk for HIV transmission or infection. Research proposals should incorporate substance use into study aims, and the objectives should address substance use prevention, screening, and/or treatment in ways that facilitate the use of HIV prevention and treatment services.

NIDA also sponsored the FOA, [Prevention and Treatment of Substance Using Populations with or at Risk for HCV](#), which focused on high-impact clinical and basic research for at-risk substance using populations, including those infected with or at risk for HIV, with a particular focus on the prevention and treatment of Hepatitis C Virus (HCV) to reduce new infections and to identify and treat existing infections more effectively. High-risk sexual behaviors, often associated with drug abuse, have been linked with HCV transmission among MSM. HCV infection is six- to eight-fold more likely in HIV-infected MSM than in those who are HIV negative.

The FOA, [Substance Use and Abuse, Risky Decision Making and HIV/AIDS](#), sponsored by NIDA and the National Institute on Alcohol Abuse and Alcoholism (NIAAA), seeks to stimulate model-driven research to understand the ways that people make decisions about engaging in behaviors that impact their risk of acquiring or transmitting HIV, or to adhere to treatments for HIV. Decision-making processes may contribute to both substance use/abuse and other HIV acquisition or

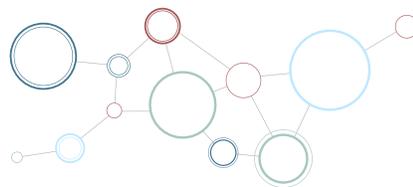
## GOAL 1

transmission risks. A better understanding of decision-making processes in the context of brain neural networks and their associated functions would lead to the development of better strategies to reduce the frequency of HIV-risk behaviors.

Additional SGM-related FOAs were sponsored by NIDA in 2016. These include the [Epidemiology of Drug Abuse](#), which encourages the development of research proposals to enhance our understanding of the nature, extent, distribution, etiology, comorbidities, and consequences of drug use, abuse, and addiction across individuals, families, communities, and diverse population groups. Also, the [Drug Abuse Prevention Intervention Research](#) FOA encourages development of proposals that employ rigorous scientific methods to test theoretically derived hypotheses to increase the scientific understanding of drug use prevention within diverse populations and settings, and across the lifespan.

### Other SGM-Related Activities

The SGMRO reached out to several components of the NIH to explore ways to include sexual orientation and gender identity (SOGI) questions in large cohort studies. These conversations are ongoing; several Institutes and Centers are considering how best to include SOGI measures in these large initiatives.





## GOAL 2

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

## Introduction



In addition to expanding research in SGM health, the NIH also must ensure that the barriers to advancing SGM health research are addressed. Better coordination of activities related to SGM health research across the NIH further highlight NIH's commitment to this area of research and facilitate its growth. In addition, the SGMRO is committed to building collaborations within the NIH to strengthen the relationships and understanding about unique issues relevant to SGM research across the agency. The SGMRO works to communicate with the extramural community about scientific areas of interest and to connect researchers and scholars with appropriate contacts across the agency. The SGMRO also provides outreach to the extramural community and other stakeholders to help educate researchers and scholars about the NIH structure and funding resources.

Components across the agency are working internally to increase communication and awareness about SGM health research. In addition, ICOs educate extramural researchers and other parts of government about the work being conducted at the NIH through conference presentations and internal collaborations.

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## Outreach, Education, and Coordination

During FY 2016, the Director of the SGMRO continued to serve as Co-Chair of the NIH Sexual and Gender Minority Research Coordinating Committee. Broad committee representation from across the NIH helped to ensure that communication was streamlined and collaborations could easily be established.

In addition, the NIH established the Sexual and Gender Minority Research Working Group (SGMRWG) of the Council of Councils, an advisory council for DPCPSI. In response to the DPCPSI and SGMRO Directors' requests, the SGMRWG of the Council of Councils will provide scientific expertise and advice to the Council on opportunities for trans-NIH collaborations, approaches for outreach to SGM researchers and researchers conducting SGM-related projects, research priorities, and other issues as needed.



*The SGMRO works to communicate with the extramural community about scientific areas of interest and to connect researchers and scholars with appropriate contacts across the agency.*

The SGMRO continued to participate in the Department of Health and Human Services (HHS) LGBT Coordinating Committee. The Committee is chaired by staff at the Office of the Assistant Secretary for Health and meets monthly to discuss LGBT issues at the Department level. In 2016, the SGMRO helped establish the HHS Research and Surveillance Working Group, a sub-committee of the HHS Coordinating Committee. This working group was convened to increase communication across the Department about SGM-related research and research-related activities. The hope is that increased communication will allow for more strategic research direction in SGM research and the elimination of potential duplicated efforts.

Several NIH representatives participated in 2016 on the Federal Interagency Working Group on Measuring Sexual Orientation and Gender Identity, coordinated by the Office of Management and Budget. From August to October of 2016, the Working Group published three papers highlighting [Current Measures of Sexual Orientation and Gender Identity in Federal Surveys](#), [Evaluations of Sexual Orientation and Gender Identity Survey Measures](#), and [Toward a Research Agenda for Measuring Sexual Orientation and Gender Identity in Federal Surveys](#).

In FY 2016, the SGMRO worked with the NIH Clinical Center to plan for the collection of gender identity data in their Electronic Medical Record system. The Clinical Center Medical Executive Committee approved changes to the system; technical requirements will be finalized in FY 2017. Also in FY 2017, the Clinical Center will begin to provide educational opportunities and training materials to ensure rollout of the new data collection approach is completed in a timely and culturally sensitive manner.

The Office of AIDS Research (OAR) coordinates the participation of several ICs in NIH-funded Centers for AIDS Research (CFARs). Several of the CFARs located throughout the United States have held various symposia dedicated to the topic of SGM health, including sessions dealing with transgender issues and HIV risk, where several advances have emerged this year.

OAR staff participated in a National HIV/AIDS Strategy (NHAS) Work Group on the Developmental Indicator for Transgender Populations. This Work Group was tasked to develop an indicator to measure progress towards achieving NHAS goals in HIV outcomes among transgender women. They also participated in the White House consultation on HIV in transgender populations in February 2016.

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The NICHD Scientific Director and Extramural Scientific Project Officers presented a talk on Scientific Issues in Differences/Disorders of Sex Development (DSD), also known as Intersexuality, on January 20, 2016, to the HHS LGBT Coordinating Committee.

The National Heart, Lung, and Blood Institute AIDS Working Group focused on refining scientific priorities and identifying scientific gaps in HIV-related heart, lung, blood, and sleep research. Because of those meetings, there were several recommendations of note that were designated as priorities in research for at-risk populations (e.g., youth, MSM, high-risk individuals). These included the retention in care, retention in care for people living with HIV, and understanding how health systems can promote retention in care for people living with HIV in at-risk populations.

In 2016, the National Institute of Allergy and Infectious Diseases (NIAID) published a manuscript entitled "[Engaging Transgender People in NIH-Funded HIV/AIDS Clinical Trials Research](#)" as part of a special supplement to the *Journal of Acquired Immune Deficiency Syndromes*. NIAID's Division of AIDS staff co-authored the paper with members of several NIH-funded HIV/AIDS Clinical Trials Networks, namely the HIV Prevention Trials Network, the Microbicide Trials Network (MTN), and the HIV Vaccine Trials Network, as well as investigators with MTN and NICHD's Adolescent Trials Network. The supplement focused on the impact of HIV in the transgender population and associated challenges of HIV prevention, while the paper addressed the different ways in which NIH-funded research networks have engaged transgender communities in their research studies. In addition, the NIAID Division of AIDS continued to convene a Cross Network Transgender Working Group (originally established in FY 2015) to help ensure that funded HIV/AIDS research networks (prevention and treatment) are culturally responsive to the needs of transgender people.

### Technical Assistance With Principal Investigators

The SGMRO serves as a point of contact for Principal Investigators (PIs) who have concerns pertaining to SGM research or questions about the NIH grant process. In addition, several referrals were made to PIs during FY 2016 to NIH Program Officers that could help discern the best fit for a given research project, and provide feedback directly to investigators.

Program Directors across several ICs provided scientific technical assistance to extramural researchers. A few examples follow of how ICs communicated with potential applicants.

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In FY 2016, the extramural scientific project officers at NICHD provided technical assistance to potential applicants interested in submitting applications to do research on SGM populations. NICHD program officers frequently communicated with program officials at other Institutes to identify the best scientific fit for pending applications. NICHD, via the NICHD Adolescent Medicine Trials Network for HIV/AIDS Interventions, conducted an [online webinar](#) for potential applicants.

NIMH Program Officers provided technical assistance to a range of potential and currently funded investigators on a wide range of topic areas pertaining to SGM health research. Specifically, program staff spoke with investigators about how to align their SGM research with NIMH's new strategic plan and provided information about NIMH's new clinical trials FOAs. NIMH co-funded two administrative supplements focused on SGM youth in the Division of Translational Research, an R21 grant focused on transgender individuals in the Division of Services and Intervention Research, and numerous grants, training awards, and administrative supplements in the Division of AIDS Research.



## Presentations

The SGMRO presented on numerous occasions in FY 2016, educating researchers, NIH staff, and the public about the establishment of the SGMRO, the history of its formation, and the goals of the NIH SGM Research Strategic Plan. Examples of engagements are highlighted below.

Internal presentations were made to the HHS LGBT Coordinating Committee, the National Institute on Minority Health and Health Disparities (NIMHD) Summer Institute, SGMRWG, NIAID, Centers for AIDS Research, and the Advisory Committee on Research on Women's Health.

External presentations included the Society for Social Work Research and Northwestern University's Institute of Sexual and Gender Minority Health and Wellbeing Inaugural State of LGBT Health Symposium. Finally, through HHS, the SGMRO presented to the LGBT Health Graduate Certificate Program at George Washington University in the fall of 2016.

In collaboration with the NIH Office of Equity, Diversity, and Inclusion (OEDI), the SGMRO helped plan several events in honor of Pride month. The Office co-sponsored events that showcased

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a local, grassroots organization, including a panel presentation that focused on HIV prevention among black MSM. This was followed by a data-centric event, at which the SGMRO Director presented on the challenges related to data collection relevant to SGM research. A final panel presentation focused on transgender health and health research that featured NIH staff, an extra-mural researcher, a patient advocate, and a transgender storyteller. Also as part of Pride month recognition, OEDI held a training presentation on transgender health that was open to the public.

### Other SGM-Related Activities

In May of 2016, the Center for Scientific Review (CSR) named an Associate Director for Diversity and Workforce Development. The Associate Director will oversee staff recruitment and development efforts, coordinate scientific policy training, and manage efforts to increase the diversity of CSR staff and its pool of reviewers, such as CSR's Early Career Reviewer Program.



The NCI sponsored The Cancer Prevention and Control Colloquia Series, with a presentation entitled "Cancer and the LGBT Community: Reporting on an Understudied Population." This series featured a distinguished professor who conducts research on cancer and SGM populations.

In September of 2016, the NIMH Division of AIDS Research participated in a research forum held in New York City entitled "What Research Do We Need to Advance Policy Related to HIV and LGBT Health?" The forum was co-sponsored by the Hunter College Center for HIV Educational Studies and Training and the LGBT Social Science and Public Policy Center at Roosevelt

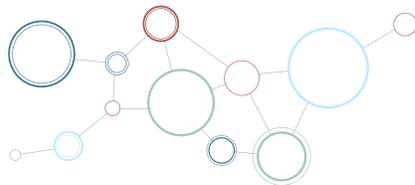
House. A program director from NIMH delivered remarks on "HIV Research Priorities and Directions at the NIMH Division of AIDS Research" and participated in a panel discussion regarding HIV-related health research among MSM populations.



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The NIMH Division of AIDS Research participated in several initiatives to help better understand the complex issues related to stigma and HIV. Staff attended the “The White House Meeting on HIV Stigma: Addressing Stigma through Research.” The meeting was co-sponsored by the NIH OAR and the White House Office of National AIDS Policy. Following this meeting, a half-day seminar was held to identify next steps in the research agenda designed to measure, monitor, and address HIV stigma and track its impact on HIV outcomes. A focus on both days was measuring HIV transmission/acquisition and the intersection of other stigmas, including racial/ethnic, sexual behavior or orientation, sex work, and gender. In September of 2016, the Division of AIDS Research also participated in a meeting entitled “HIV Stigma Reduction Summit.” The meeting was sponsored by the Presidential Advisory Council on HIV/AIDS’ Disparities Subcommittee. An NIMH staff member delivered remarks on “HIV Stigma Research Overview” and participated in a panel discussion regarding measurement, mechanisms, and intervention research.

NICHD sponsored a presentation on lessons learned in the study of Congenital Adrenal Hyperplasia by an intramural senior investigator at the Endocrine Society Plenary Lecture. NICHD also sponsored research that led to “Management of Congenital Adrenal Hyperplasia Meet the Expert Presentation,” presented at the 17th International Congress of Endocrinology and 15th Annual Conference of Chinese Society of Endocrinology (ICE/CSE) in Beijing, China, by a senior investigator in the NICHD intramural program.



## GOAL 3

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

## Introduction

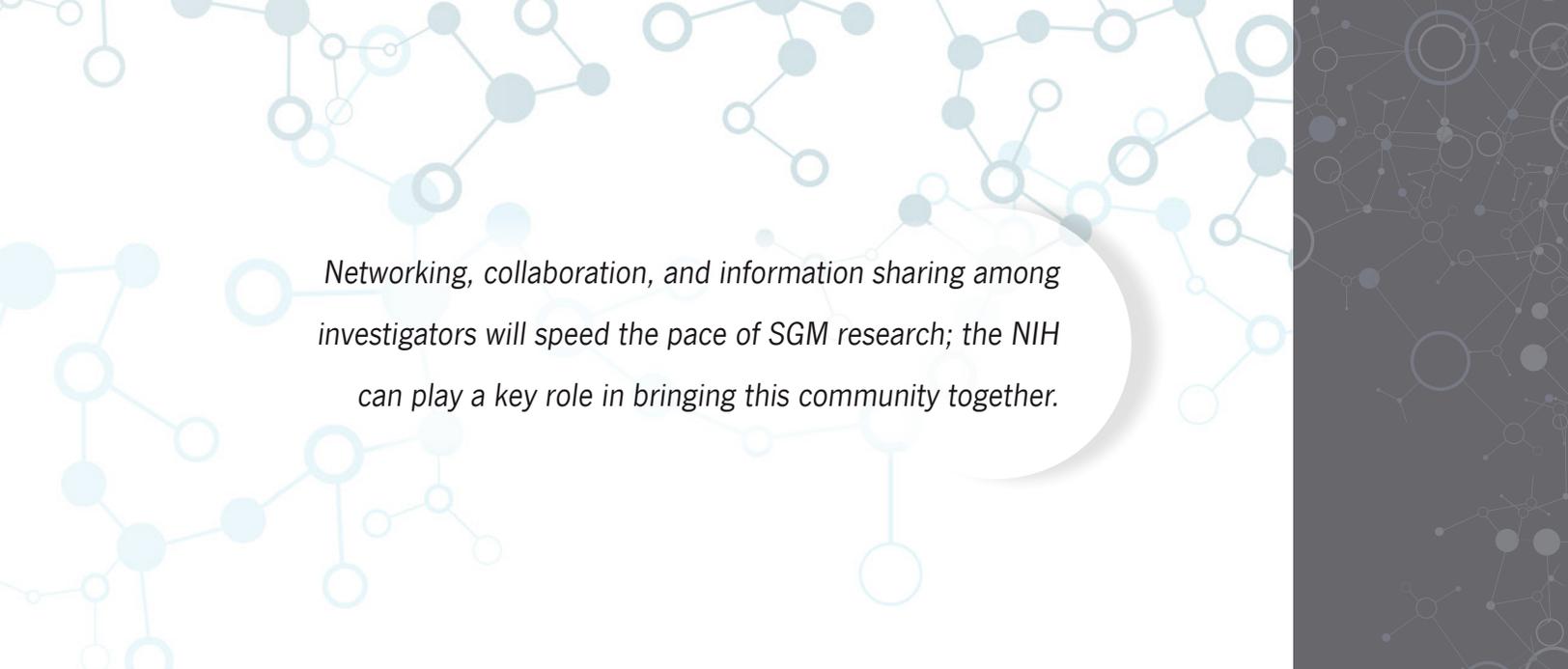


As reported in the Strategic Plan, strengthening the community of researchers and scholars who conduct research relevant to SGM health and well-being has emerged as an NIH priority. Networking, collaboration, and information sharing among investigators will speed the pace of SGM research; the NIH can play a key role in bringing this community together. In addition, bolstering the SGM research community will ensure that the NIH is well-poised to support high-quality and innovative work in SGM health research, with a pool of research experts upon whom it can call for insight and perspectives specific to the field. Here, we report on activities specific to mentoring and developing such researchers.

## Mentoring Researchers

In 2016, the SGMRO presented at the NIMHD Summer Institute and organized an informal get together with a group of scholars conducting SGM-related health disparities research to answer questions about the NIH grants process. Of the approximate 50 scholars who attended the Summer Institute, five are conducting research with SGM populations.

The Office of Intramural Training and Education (OITE) in the NIH OD aims to enhance the training experience of students and fellows across the NIH. More specifically, they focus on helping NIH trainees develop scientific and professional skills that will enable them to become leaders in the biomedical research community. Many OITE workshops and science skills tutorials are now available online to trainees across the United States and around the world. The NIH Academy, a program of OITE, offers trainees the opportunity to learn about health disparities, enhance their knowledge of gaps in health outcomes, and investigate what is being done to address health disparity issues. 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. Over the last several years, the Academy's curriculum has included sessions on health disparities in SGM communities, including SGM youth. The NIH Academy also includes a Diversity Course with a workshop specific to LGBT populations and health.



*Networking, collaboration, and information sharing among investigators will speed the pace of SGM research; the NIH can play a key role in bringing this community together.*

The OITE also sponsors the LGBT-Fellows and Friends affinity group for LGBT trainees and supporters on the NIH campus. This group helps its members thrive in their professional and personal lives by addressing issues unique to the LGBT community. LGBT-Fellows and Friends organizes seminars and workshops to educate the public on LGBT issues, provides professional development opportunities, and offers social events to develop professional and personal networks.

Career development programs are an effective way to support researchers and scholars. The National Institute of Diabetes and Digestive and Kidney Disorders has two urology-focused institutional career development programs with SGM-related projects.

The National Institute of General Medical Sciences (NIGMS) sponsors the Mississippi IDeA Network of Biomedical Research Excellence (INBRE) award that supports the improvement of Mississippi's biomedical research infrastructure and the health of its communities. The INBRE network develops a workforce to address Mississippi's health problems and reach the state's most impoverished and underserved areas via the building and strengthening of its research capacity.

One component of the INBRE, the Community Engagement and Training Core, provides training to minority students in public health and community outreach through partnerships with public health organizations that reach out to underserved communities in Mississippi, including SGM communities. The students develop research proposals that integrate their biomedical research and public health interests, enhancing their exposure to research opportunities and careers. They also have opportunities to gain real-world experience in public health, including health screenings, public health programming, certifications in HIV testing and counseling, and phlebotomy.

In FY 2016, OBSSR provided funding and mentoring for a Post-Baccalaureate Intramural Research Training Award Fellow interested in SGM research. The awardee has since taken a full-time position at the NIH that focuses on SGM-related activities.

## **Conferences/Meetings**

Representatives from the NCI attended a number of sessions at the Ninth American Association for Cancer Research (AACR) Conference on The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved. An NCI program director chaired the session on

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cancer in SGM communities, which is the first of its nature at an AACR conference. The session included discussion of the unique issues of cancer survivorship among sexual minorities.

An NICHD extramural scientific project officer presented at several conferences and workshops that provided information on the NIH research funding process (with emphasis on making the process more transparent for junior researchers) and on securing NIH research funding. Presentations were made during the following meetings and webinars:

- Psychosocial Factors in Population Change meetings, Washington, DC, April 2016
- Meeting on Sexual Coercion and Domestic Violence, University of Pittsburgh, May 2016
- Social and Behavioral Science Research Network Meeting, Washington, DC October 2016
- American Psychological Association webinar on NIH grant writing, Washington, DC October 2016
- A webinar with University of Minnesota, specifically on the SGM FOAs.

The NIMH Division of AIDS Research participated in a working meeting entitled “PrEP Vision 2016” that identified and explored approaches to speed up the implementation of HIV PrEP among MSM in the United States. Staff contributed to the working meeting discussion and priority-setting activities.

NIMH and NIAID co-sponsored a meeting entitled “Ethical, Legal, and Policy Challenges in HIV Research with Key Populations.” A substantial portion of the meeting focused on SGM populations. Specifically, there were presentations on how to work with institutional review boards when conducting research with SGM populations and how to ethically recruit and retain SGM populations in research.

NIMH staff presented on NIMH priorities regarding adolescent HIV prevention research at the Society for Adolescent Health and Medicine annual meeting in Washington, DC, in March of 2016. The presentation was part of a larger session on adolescent HIV prevention. Staff reported on NIMH’s research priorities regarding HIV prevention among SGM youth.

In 2016, the National Institute on Aging supported a preconference workshop at the Gerontological Society of America (GSA) national meeting that focused on the development and implementation of evidence-based practices to address the aging and health needs of LGBT older adults.



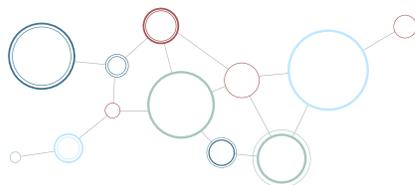
This was the latest in a series of GSA workshops to identify effective methods for translating new and effective health interventions to real-world settings.

This year, NIAAA conducted a panel entitled “Recent Advances in the Understanding of Alcohol-Related HIV Risk Among Men Who Have Sex with Men: Steps Toward Enhanced Prevention Tools” at the Annual Conference of the Research Society on Alcoholism (RSOA) held in New Orleans, Louisiana. NIAAA staff also organized and moderated a Satellite Meeting at RSOA. One of the presentations was given by an NIAAA grantee from Old Dominion University entitled “Sexual Minority Stress, Alcohol Use, and Intimate Partner Violence Over Time Among Lesbian Women.”

### Other SGM-Related Activities

NICHD’s Intramural Research Program continued to see patients with SGM/DSD and their families in the NIH Clinical Research Center-based fellowship training programs in pediatric endocrinology and medical genetics. This Intramural Research Program also is actively involved in the transnational efforts to advance SGM research and training by participating in a consortium of endocrine training programs that have related, active clinical programs.

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## GOAL 4

# Evaluate Progress on Advancing SGM Research

## Introduction



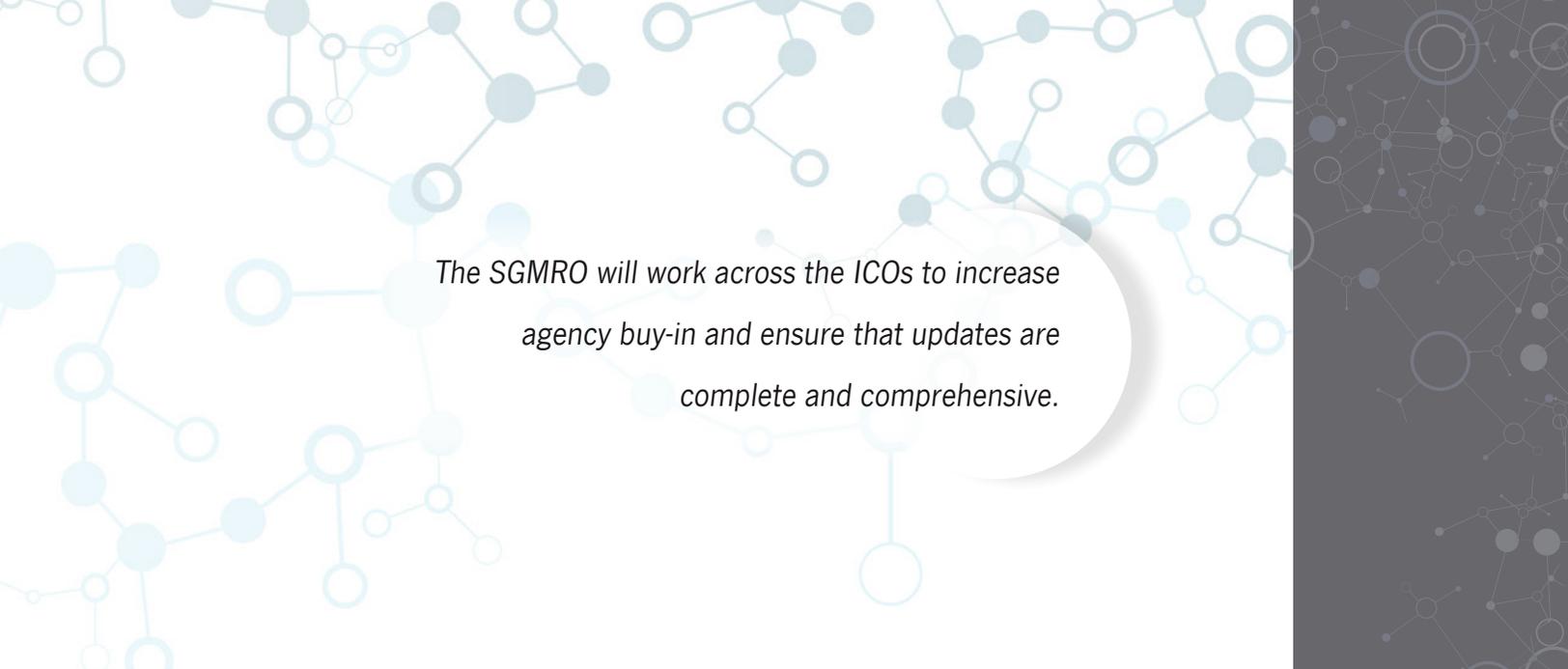
As noted in the Strategic Plan, the NIH will evaluate its efforts on an annual basis to ensure that they remain on track and meet milestones. Both a Portfolio Analysis highlighting SGM-related research projects, along with an Annual Report capturing other SGM-related work at the NIH, will be published each year. Existing internal tracking tools will be updated to ensure that SGM tracking reports are accurate, complete, transparent, and timely. As outlined in the SGM Research Strategic Plan, the NIH will convene a panel of SGM health research experts to review NIH's mid-course progress on the Plan. The SGMRO will work across the ICOs to increase agency buy-in and ensure that updates are complete and comprehensive.

## 2015 Portfolio Analysis

Using RePORTER data, the SGMRO compiled data from the 2015 Federal Fiscal Year (October 1, 2014–September 30, 2015) to create the 2015 SGM Portfolio Analysis. The 301 projects identified in [RePORTER](#) that comprise the NIH SGM portfolio for 2015 were selected by using NIH's Research, Condition, and Disease Categorization ([RCDC](#)) process.

"Sexual and Gender Minorities (SGM/LGBT)" was added to the official list of 265 RCDC categories in FY 2015, and as a result, this estimate of SGM spending constitutes the first ever report of those data using RCDC codes. RCDC uses text data mining (categorizing and clustering using words and multiword phrases), in conjunction with a list of concepts and synonyms selected by NIH scientific experts to define a research category. Reflecting NIH's inclusive approach to SGM health research, the RCDC fingerprint involves key words and concepts that encompass LGBT 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 projects that address people with DSD, sometimes known as intersex.

The reported RCDC funding is an estimate based on the SGM fingerprint, text mining approach, and attribution of all grant funds in a given category. The RCDC SGM category is new; therefore, no historical funding trends can be reported at this time.

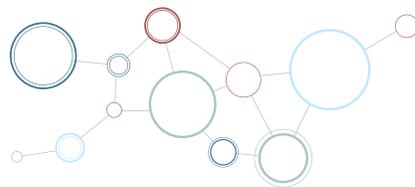


*The SGMRO will work across the ICOs to increase agency buy-in and ensure that updates are complete and comprehensive.*

## **RCDC Validation and Refinement**

The RCDC process is a targeted search of all applications for funding received during a given time period. The search is conducted using key terms that are weighted (known as a fingerprint). When a given project reaches a threshold for those terms, it is tagged as belonging to that RCDC category, in this case the SGM fingerprint.

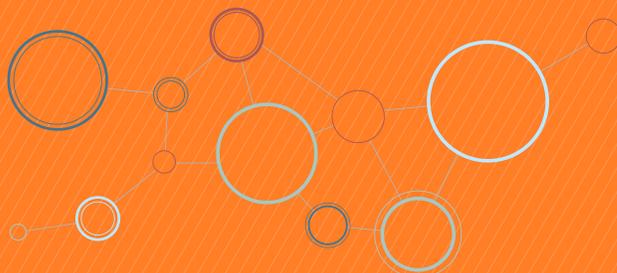
The RCDC process relies solely on the clarity and specificity of the text provided and uses new trans-NIH definitions. For these reasons, in viewing the RCDC project listings, researchers might agree or disagree with the categories in which their projects appear. The SGMRO works across the NIH ICOs to validate and refine the SGM fingerprint to ensure that the most accurate data are available to the public through the NIH Report website. The most recent validation of these data was performed in FY 2016.



A network diagram background consisting of interconnected nodes and lines, transitioning from a dark grey on the left to a light blue on the right. The nodes vary in size and are connected by thin lines, creating a complex web-like structure.

## Conclusion

*The NIH is committed to expanding the field of SGM-related health research and strengthening the community of scholars and researchers who seek to make a career in this scientific field of inquiry. Since the release of the NIH SGM Research Strategic Plan (FY 2016–2020), much has been accomplished across the agency. However, there is much work to be done. The NIH will continue to track its progress across the four Goal Areas of the SGM Strategic Plan, and seek to increase and improve research in SGM health.*

A network diagram foreground consisting of interconnected nodes and lines, rendered in white and light blue. The nodes vary in size and are connected by thin lines, creating a complex web-like structure.

# Appendix A

## NIH Institutes and Centers

### NIH Offices

NIH Office of the Director (OD)

### NIH Institutes

National Cancer Institute (NCI)

National Eye Institute (NEI)

National Heart, Lung, and Blood Institute (NHLBI)

National Human Genome Research Institute (NHGRI)

National Institute on Aging (NIA)

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

National Institute of Allergy and Infectious Diseases (NIAID)

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

National Institute of Biomedical Imaging and Bioengineering (NIBIB)

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institute on Deafness and Other Communication Disorders (NIDCD)

National Institute of Dental and Craniofacial Research (NIDCR)

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

National Institute on Drug Abuse (NIDA)

National Institute of Environmental Health Sciences (NIEHS)

National Institute of General Medical Sciences (NIGMS)

National Institute of Mental Health (NIMH)

National Institute on Minority Health and Health Disparities (NIMHD)

National Institute of Neurological Disorders and Stroke (NINDS)

National Institute of Nursing Research (NINR)

National Library of Medicine (NLM)

### NIH Centers

NIH Clinical Center (CC)

Center for Information Technology (CIT)

Center for Scientific Review (CSR)

Fogarty International Center (FIC)

National Center for Advancing Translational Sciences (NCATS)

National Center for Complementary and Integrative Health (NCCIH)



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