

NIH National Institutes of Health Sexual & Gender Minority Research Office

### Sexual & Gender Minority Research Office ANNUAL REPORT

### **Fiscal Year**

### **Table of Contents**

Introduction1
Goal One: Advance Rigorous Research on the Health of SGM Populations in Both the Extramural and Intramural Research Communities
Funding Opportunity Announcements and Notices
Goal Two: Expand SGM Health Research by Fostering Partnerships and Collaborations with a Strategic Array of Internal and External Stakeholders
Partnership and Engagement7
Communications9
Presentations to NIH and Other Government Organizations
Goal Three: Foster a Highly Skilled and Diverse Workforce in SGM Health Research12
Removing Barriers to Equity in the Workforce12Education14Connecting with Researchers15Other Goal Three–Related Activities17
Goal Four: Encourage Data Collection Related to SGM Populations in Research and the Health Research Workforce
Closing Thoughts

### Introduction

The Sexual & Gender Minority Research Office (SGMRO) was established in 2015 to coordinate sexual and gender minority (SGM) health-related research and activities at the National Institutes of Health (NIH) by working directly with the agency's Institutes, Centers, and Offices (ICOs). Each year, the SGMRO publishes a portfolio analysis that quantitatively describes SGM research funded by the NIH in a given fiscal year (FY). The SGMRO also provides a qualitative description of a representative sample of SGM health- and research-related activities and initiatives occurring across the NIH in this, the Annual Report. The report is organized around the four operational strategic goal areas of the <u>NIH Strategic Plan to Advance Research on the Health and Well-being of Sexual & Gender Minorities: FYs 2021–2025</u>.

Of particular relevance for this report, the NIH released an updated definition of SGM populations in Notice <u>NOT-OD-19-139</u> in August 2019 to better clarify the populations that fall under the SGM umbrella for NIH-supported research. It reads as follows:

SGM populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with a difference in sex development are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.

# Goal One

Advance Rigorous Research on the Health of SGM Populations in Both the Extramural and Intramural Research Communities

#### FUNDING OPPORTUNITY ANNOUNCEMENTS AND NOTICES

The NIH supported SGM health research through numerous funding opportunities in FY 2021. The agency executed the <u>SGM Administrative Supplements Program</u> for the sixth year, awarding 12 meritorious supplements whose parent grants are at six different NIH Institutes. In addition to Institute backing, the SGMRO, the Office of AIDS Research (OAR), the Office of Behavioral and Social Sciences Research (OBSSR), the Office of Disease Prevention (ODP), the Office of Research on Women's Health (ORWH), and the Tribal Health Research Office (THRO)—all within the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) in the NIH Office of the Director (OD)—provided co-funding. The investment in these projects totaled \$1,172,082, bringing the grand total of all SGM supplement funding since the program's inception in 2015 to \$7,258,368. These monies have been disbursed by 19 ICOs to subsidize 76 unique supplements whose principal investigators conduct research across 26 U.S. states; Washington, D.C.; and Uganda.

The National Institute on Minority Health and Health Disparities (NIMHD) and 19 co-signing ICOs continued to solicit epidemiological, etiological, intervention, implementation, and evaluation research related to the health of SGM populations through the Notice of Special Interest (NOSI)<sup>1</sup> <u>NOT-MD-19-001</u>. This NOSI has been active since March 2019.

In FY 2021, multiple ICOs published new funding opportunity announcements (FOAs) or maintained support for existing FOAs soliciting research focused on or relevant to the health and well-being of SGM populations, including the following:

- <u>American Women: Assessing Risk Epidemiologically (AWARE)</u>
- <u>Centers for Multiple Chronic Diseases Associated with Health Disparities: Prevention, Treatment, and Management</u>
- <u>Comprehensive Care for Adults with Type 2 Diabetes Mellitus from Populations with Health Disparities</u>
- Dyadic Interpersonal Processes and Biopsychosocial Outcomes (<u>R01 Clinical Trials Not Allowed</u> and <u>R01 Basic Experimental Studies with Humans</u>)

<sup>&</sup>lt;sup>1</sup> NOSIs highlight scientific topics of particular interest to one or more NIH funding components and direct applicants to relevant active funding opportunity announcements for submission of applications. More information can be found in <u>NOT-OD-19-107</u>.

- <u>Effectiveness of Implementing Sustainable Evidence-Based Mental Health Practices in Low-</u> <u>Resource Settings to Achieve Mental Health Equity for Traditionally Underserved Populations and</u> <u>Implementing and Sustaining Evidence-Based Mental Health Practices in Low-Resource Settings</u> <u>to Achieve Equity in Outcomes</u>
- <u>Effectiveness of School-Based Health Centers to Advance Health Equity</u>
- Engaging the Dental Workforce to End the HIV Epidemic in the U.S.
- Faculty Institutional Recruitment for Sustainable Transformation (FIRST)
- Firearm Injury and Mortality Prevention Research (<u>R01 Clinical Trial Optional</u> and <u>R21/R33 Clinical</u> <u>Trial Optional</u>)
- Initiation of a Mental Health Family Navigator Model to Promote Early Access, Engagement and <u>Coordination of Needed Mental Health Services for Children and Adolescents</u>
- Innovative Multi-Level Approaches and Strategies to Prevent, Test and Treat HIV in Primary Care Settings in Health Disparity Populations in Geographic Hot Spots in the United States
- Interventions for Stigma Reduction to Improve HIV/AIDS Prevention, Treatment and Care in Lowand Middle-Income Countries
- Limited Interaction Targeted Epidemiology (LITE-2): To Advance HIV Prevention
- Reducing Stigma Related to Drug Use in Human Service Settings (<u>R21 Clinical Trial Optional</u> and <u>R34 Clinical Trial Required</u>)
- The Intersection of Sex and Gender Influences on Health and Disease
- The Role of Work in Health Disparities in the U.S.
- <u>Transformative Research to Address Health Disparities and Advance Health Equity</u> and
   <u>Transformative Research to Address Health Disparities and Advance Health Equity at Minority
   Serving Institutions
  </u>
- Understanding and Addressing the Impact of Structural Racism and Discrimination on Minority
   Health and Health Disparities

The NIH promoted SGM research interests at the agency by releasing a variety of relevant notices, examples of which included the following:

- NOSI: Administrative Supplements for Research on Sex/Gender Influences
- NOSI: Administrative Supplements to NIMHD Awards for Research on HIV/AIDS in Populations
   that Experience Health Disparities
- NOSI: Improving Patient Adherence to Treatment and Prevention Regimens to Promote Health
- NOSI: Multi-Level HIV Prevention Interventions for Individuals at the Highest Risk of HIV Infection
- NOSI: National Institute on Deafness and Other Communication Disorders (NIDCD) Health Disparities and Inequities Research
- NOSI: Promoting Viral Suppression among Individuals from Health Disparity Populations Engaged in HIV Care
- NOSI: Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations
- Notice of Intent to Publish a FOA for Adolescent Medicine Trials Network for HIV/AIDS
   Intervention (ATN) Scientific Leadership Center and Operations and Collaborations Center

The NIH also continued to issue NOSIs and FOAs soliciting research related to coronavirus disease 2019 (COVID-19); its impact; and its mitigation in disparity populations, including sexual and gender minorities. These included the following:

- <u>Emergency Award: RADx-UP—Social, Ethical, and Behavioral Implications (SEBI) Research on</u> <u>Disparities in COVID-19 Testing Among Underserved and Vulnerable Populations</u>
- Emergency Awards: Community-Engaged COVID-19 Testing Interventions Among Underserved and Vulnerable Populations—RADx-UP Phase II
- NOSI: Administrative Supplements for Rapid Acceleration of Diagnostics-Underserved Populations (RADx-UP) Phase I Projects to Address Vaccine Hesitancy and Uptake
- NOSI: Emergency Competitive Revisions for Community-Engaged COVID-19 Testing Interventions Among Underserved and Vulnerable Populations—RADx-UP Phase II
- NOSI: Research on the Impact of the COVID-19 Pandemic and Risks for Abuse and Injury Among Vulnerable Children and Youth

During FY 2021, NIMHD's National Advisory Council on Minority Health and Health Disparities approved several research concepts with relevance to SGM health that may eventually lead to corresponding FOAs. Highlights of the approved research concepts included the following:

- <u>Community-Level Interventions to Improve Minority Health and Reduce Health Disparities</u>
- Innovative Health Care Models for Persons with Multiple Chronic Conditions from Populations
   That Experience Health Disparities
- <u>Practice-Based Clinical Research Networks to Improve Health Care for Populations That</u> <u>Experience Health Disparities</u>
- <u>Small Business Initiative (Small Business Innovation Research and Small Business Technology</u> <u>Transfer—SBIR/STTR)</u>

#### **OTHER GOAL ONE-RELATED ACTIVITIES**

The <u>SGM Health Disparities Research Framework</u> was officially published in FY 2021. Adapted from NIMHD's <u>Minority Health and Health Disparities Research Framework</u>, the SGM-focused version is intended to highlight the many unique factors that may exert a significant influence on the health outcomes of LGBTQI+ individuals. The goal of this framework is to inform potential and current SGM researchers of salient issues for consideration at the individual, interpersonal, community, and societal levels.

The Committee on Population of the National Academies of Sciences, Engineering, and Medicine (NASEM) officially released its report on <u>Understanding the Well-Being of LGBTQI+ Populations</u> in October 2020. Co-funded by the SGMRO, this report reviews the available evidence base on the health and status of sexual and gender diverse people,<sup>2</sup> identifies critical gaps in our understanding of their experiences and challenges, and offers recommendations for addressing present and future research needs related to their well-being across the life course. Throughout FY 2021, representatives from NASEM presented to various audiences to raise awareness of the report and provide a more in-depth explanation of its findings and recommendations.

<sup>&</sup>lt;sup>2</sup> In the NASEM report, the term "sexual and gender diverse," or "SGD," is used to acknowledge the broad spectrum of natural human variation in sexual orientation, gender identity, and sex development. SGD populations in the NASEM report are analogous to SGM populations for NIH-supported research.

The NIH Scientific Workshop on Violence & Related Health Outcomes in SGM Communities was held in four phases in FY 2021 with the support and participation of an array of NIH ICOs<sup>3</sup> and representatives from academia, nonprofit organizations, advocacy groups, federal agencies, and other segments of the scientific and clinical communities. The overarching goal of the workshop was to enhance the knowledge base on violence against SGM individuals and elucidate opportunities to expand research in the field. Phase I consisted of a Request for Information from the public on the workshop's agenda and framework. In Phase II, subject matter experts and stakeholders engaged in discussions about the current state of violence research in four domains: family of origin abuse, peer and friend victimization, romantic and sexual partner violence, and community violence. The results of these discussions are recapitulated in the Phase II Summary Document. In Phase III, expert invitees took part in five working groups that discussed research opportunities in five key research areas: demographics and epidemiology, risk factors and pathways, preventive interventions, treatment-focused interventions, and ethics and logistical challenges. Phase III results were presented and further refined in Phase IV, the final open report-out session. Specific research opportunities identified by each of the research area working groups are fleshed out in greater detail in the Final Workshop Summary Document.

Grantees from the National Institute on Aging (NIA) held a symposium titled "Beyond Sex: Gender, LGBTQ, and Alzheimer's Disease and Related Dementias" at the Gerontological Society of America's National Meeting in November 2020.

In FY 2020, OAR and the National Institute of Mental Health (NIMH) Division of AIDS Research co-organized an <u>HIV-related intersectional stigma workshop</u> that aimed to advance HIV prevention and treatment science, inform the <u>Ending the HIV Epidemic in the U.S.</u> initiative, and bolster HIV efforts worldwide. SGM populations, issues, and needs were highlighted in several presentations throughout the workshop. In FY 2021, the <u>workshop summary report</u> describing the workshop's phases, activities, and outcomes was officially published. Related to this effort, representatives from ICOs across the NIH discussed HIV-related stigma research as a priority at the agency in a 2021 <u>manuscript</u>. The SGMRO contributed information to the manuscript regarding SGM-specific considerations related to HIV stigma and opportunities to mitigate HIV stigma-related disparities experienced by members of the SGM community.

Staff members of the NIMH, NIMHD, and SGMRO co-authored a <u>commentary</u> on intersectionality in public health research that was published in January 2021. This article recognized the importance of conducting intersectional research to better understand and improve the health of those affected by interlocking social and structural systems of privilege and oppression, such as SGM people of color. It also called for more studies to comparatively assess the effect of intersectionality on health, research that includes potential explanatory determinants and pathways from the outset, and research that examines intersectionality with methods that can accommodate the requisite complexity and analyze the physical measurements, surveys, and electronic health records contained in the data set composed by the *All of Us* Research Program (*All of Us*). Active research projects using these data are centered on different dimensions of SGM health and well-being, such as cardiovascular health, sleep, aging, neurological disease, COVID-19-related disparities in well-being, health care access and usage, and cancer.

The National Human Genome Research Institute (NHGRI) continued to coordinate and fund the Electronic Medical Records and Genomics (<u>eMERGE</u>) Network, a U.S. medical research consortium

<sup>&</sup>lt;sup>3</sup> SGMRO was the primary sponsor and coordinator of this workshop. Co-sponsors included NIMHD, OBSSR, the National Institute on Aging, National Institute on Alcohol Abuse and Alcoholism, National Institute of Mental Health, National Institute of Nursing Research, and the *All of Us* Research Program.

supporting genomic medicine implementation. In its SGM-focused work, eMERGE seeks to understand further how LGBTQI+ people interpret genomics-informed disease risk estimates and assessments and how best to deliver this information. The results of both lines of inquiry could shed light on pertinent barriers and optimal delivery methods and ultimately improve the use of genomic risk estimates in health care decisions among SGM populations.

In FY 2021, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) launched the STrategies to enRich Inclusion and achieVe Equity (STRIVE) Initiative. Led by the NICHD Office of Health Equity, STRIVE focuses on three key areas: (1) ensuring equity, diversity, and inclusion (EDI) within NICHD's workforce; (2) enhancing opportunities for EDI in the broader scientific workforce and among trainees; and (3) planning, conducting, and supporting health disparities research. STRIVE's Health Disparities Research Committee organized and NICHD hosted the STRIVE for Change Workshop Series, bringing together federal and external stakeholders to discuss crosscutting approaches to health disparities research across populations and the lifespan. SGM-relevant topics discussed at the workshop included health inequities, biases, gender diversity, social and cultural identity, and intersectionality. The committee is currently analyzing NICHD's health disparities research portfolio, which includes an evaluation of SGM health research investments and the inclusion of SGM communities in Institute-supported research. The committee will identify research priorities for NICHD and provide leadership with recommendations to guide the Institute's health disparities research agenda, contribute to policy development, and monitor implementation and progress of an action plan that will complement the NICHD Strategic Plan and inform future directions.

The ODP launched the ADVANCE initiative to develop and test new interventions and strategies to disseminate existing interventions that address leading risk factors for death and disability in health disparity populations, including SGM people. The initiative is driven and supported by 24 participating ICOs whose efforts are coordinated by the ODP. Workgroups will focus on cardiometabolic issues; alcohol, tobacco, and other drugs; cancer; and mental health. SGMRO personnel will participate in the workgroups on mental health and alcohol, tobacco, and other drugs. In FY 2021, the ODP distributed a web-based survey among the participating ICOs to assess ICO-specific interests in the leading risk factors, preventive services related to the leading risk factors and causes of death, and health disparity populations.

# **Goal Two**

Expand SGM Health Research by Fostering Partnerships and Collaborations with a Strategic Array of Internal and External Stakeholders

#### PARTNERSHIP AND ENGAGEMENT

As part of its work to advance SGM health research, the NIH initiates, organizes, leads, and takes part in committees, working groups, and task forces within the agency and across the U.S. Department of Health and Human Services (HHS), the Federal Government, and the extramural community. The HHS-Wide Stigma Workgroup is a collaboration between partners at 15 NIH ICOs, the Centers for Disease Control and Prevention (CDC), U.S. Food and Drug Administration (FDA), Health Resources and Services Administration (HRSA), Indian Health Service, and the Substance Abuse and Mental Health Services Administration. The workgroup promotes crosscutting stigma research and related activities and seeks to enhance opportunities for knowledge transfer and collaborative learning in the field of stigma and discrimination research throughout the Department. In FY 2021, the group featured presentations on institutional gender identity affirmation and equity, diversity, and inclusion. An SGMRO representative sits on the workgroup's steering committee to ensure ongoing consideration and inclusion of SGM needs and concerns related to stigma in its activities.

The HHS Panel on Antiretroviral Guidelines for Adults and Adolescents is a working group of the OAR Advisory Council and currently has representation from NICHD, the National Institute of Allergy and Infectious Diseases (NIAID), the NIH Clinical Center, CDC, FDA, and HRSA. The primary goal of the panel is to provide HIV care practitioners with recommendations based on current knowledge of antiretroviral drugs used to treat adults and adolescents with HIV in the United States. The panel published <u>Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV</u>, which are updated as new information becomes available. The guidelines proffer recommendations and considerations for SGM adolescents, young adults, and adults, particularly transgender people and men who have sex with men (MSM). Of particular relevance to LGBTQI+ communities, in June 2021, the panel updated guideline sections on adolescents and young adults with HIV, women with HIV (including SGM individuals assigned female at birth), and substance use disorder and HIV.

The HHS LGBTQI+ Coordinating Committee is a venue for establishing and strengthening collaboration and communication across the department in the context of SGM health, human services, policy, research, and other relevant emerging issues. The committee has been reinvigorated under the new administration and will work to make progress on activities and policies of concern

to the SGM community. A new committee structure with political appointees as co-chairs has been established, and the SGMRO Director serves as one of the committee's executive directors.

NIAID oversees several groups that focus specifically on the representation of transgender persons in HIV/AIDS research. NIAID's Division of AIDS Cross-Network Transgender Working Group (CNTWG), now in its eighth year, works to create an HIV research environment that promotes transgender inclusion and supports collaboration and information exchange related to transgender issues across the NIH-funded HIV/AIDS Clinical Trials Networks. The Inter-Centers for AIDS Research (CFAR) Transgender Health Working Group was formed in 2021. This group gathers the knowledge and resources of researchers and communities across the CFARs to advance transgender health–related science, support community empowerment and collaboration, and develop and strengthen networks.

Scientific interest groups, or <u>SIGs</u>, continued to serve as important forums for sparking discussions and collaborations in specific research areas among members of the intramural and extramural scientific communities. The <u>NIH SGM Health SIG</u> is an assembly of scientists from the NIH Intramural Research Program and extramural researchers. It provides a platform for connecting and engaging those interested in SGM health and research. The SGMRO and the National Heart, Lung, and Blood Institute (NHLBI) co-lead the planning and implementation of SIG activities, along with representatives from the National Cancer Institute (NCI), the Office of Equity, Diversity, and Inclusion (OEDI), and the Office of Intramural Training and Education (OITE). The SIG launched in January 2021, and it is made up of around 40 percent faculty and around 30 percent students, fellows, or trainees; extramural researchers compose about 80 percent of the group. The SIG held two open virtual meetings in the group's initial year, one of which offered an overview of *All of Us*, the program's Researcher Workbench, an example of an active project using the *All of Us* data set, and an *All of Us*–led networking session.

The <u>NIH Stigma SIG</u> comprises participants from a broad range of NIH ICOs who share an interest in crosscutting, theoretically driven research that explores the phenomenon of stigma, its measurement, mechanisms and pathways by which it adversely affects health outcomes, and potential means of mitigating it. The SIG maintains a strong focus on issues of high salience to SGM health and wellbeing, and the SGMRO is represented in the SIG's Leadership Group. FY 2021 presentation topics included the history and impact of health-related stigma and mental illness stigma, stigma inequities, stigma associated with intellectual and developmental disabilities, intersectional stigma in cancer patients with HIV in India, and strategies to address stigma; stigmatization in SGM communities was specifically explored in many of these presentations. In FY 2021, NIMH partnered with the National Institute on Drug Abuse (NIDA), the Fogarty International Center (Fogarty), and the Stigma SIG to develop the <u>Stigma and Discrimination Research Toolkit</u>, a publicly available collection of evidence, frameworks, measures, definitions, and resources related to stigma and discrimination research.

The ORWH coordinates the <u>Sex and Gender in Health and Disease SIG (SGHD SIG)</u>, which aims to promote information exchange and interaction among NIH scientists who work on or are interested in sex as a biological variable, gender as a social construct, or the intersection of sex and gender, and their influence on health and disease outcomes. In FY 2021, the SGHD SIG hosted webinars that were recorded, highlighting <u>findings</u> on mental health from the NASEM report on sexual and gender diverse (SGD) populations, primary cell <u>models</u> to evaluate sex in HIV latency and cure strategies, and the <u>role</u> of sexual acceptability in contraceptive choices and behavior, all of which are highly relevant subjects in SGM health research.

The NIH also works to expand research by facilitating engagement among the agency, current and potential investigators, and members and representatives of the SGM community. The SGMRO hosted its second <u>SGM Health Research Listening Session</u> in November 2020. This event again assembled representatives from the research, health, and health advocacy sectors in an effort to better understand the needs, concerns, and priorities of sexual and gender minorities from a community perspective. In addition to the SGMRO, leadership from the NICHD, NIDA, NIMH, NIMHD, OAR, and the Scientific Workforce Diversity (SWD) Office provided opening remarks and remained in attendance to hear the roundtable discussion. The major themes and topics from the listening session and the post-session request for public feedback, including gaps in research for specific SGM subpopulations, are described in more detail in the <u>Summary Document</u>.

The NIMHD provided funding for the 2021 National LGBTQ Health Conference, which convened leading researchers, practitioners, trainees, and students for the purpose of bridging research and practice in addressing SGM health disparities. The goals of the conference were to increase participation by traditionally underrepresented groups in science, including women and transgender people, racial and ethnic minority groups, and people with disabilities; and to catalyze research to reduce and eliminate health disparities among LGBTQ populations. The conference was a unique opportunity to gather the best knowledge and practices in the field to inform efforts to improve the lives of SGM persons with a keen eye toward intersectionality.

Participant-centric engagement represents a substantial shift in large biomedical research initiatives which, until recently, had insufficient community and participant involvement. *All of Us* has nine national engagement partners that use their extensive network of more than 270 organizations to fortify the Program's existing network of trusted community organizations, provide a vital sounding board to shape program activities and direction, lend their expertise to help motivate diverse communities to enroll and remain engaged with the program, engage with researchers from underrepresented groups like SGM populations, and help advance the science of engagement. In FY 2021, they participated in the Bi+ Empowerment Conference: A Uniting, Supportive Experience (BECAUSE); the Molecular Medicine Tri-Conference; and Gay and Lesbian Alliance (GALA), GLMA: Health Professionals Advancing LGBTQ Equality, and Pride events. The *All of Us*-funded SGM-focused PRIDEnet team offers cultural competency and humility training, provides technical assistance to *All of Us* consortium members, and co-develops intersectionality training with other engagement partners.

#### COMMUNICATIONS

One important way to sow the seeds for collaboration and stimulate discussion of novel ideas among the SGM research community is through presentation of information and knowledge. NIAID's CNTWG presented on advancing transgender inclusion through systemic change at the October 2020 U.S. Conference on HIV/AIDS.

The OAR Director presented at the 17th National African American MSM Leadership Conference in January 2021. OITE, OAR, and the SGMRO co-supported the February 2021 <u>Health Science</u> <u>Communications and Policy Virtual Program</u>. The OAR Deputy Director and the SGMRO Director presented at this workshop. The Directors of OAR and SGMRO also jointly authored a <u>blog</u> titled "Identifying and Overcoming Barriers to Transgender HIV Testing" in April 2021. The principal strategist of the OEDI's <u>SGM Portfolio</u> was a keynote speaker at the Gender Spectrum Annual Conference in September 2021. Gender Spectrum is an organization working to help families, institutions, and other organizations increase their understanding of gender and consider the implications that evolving views of gender have for everyone.

The NIMH Office for Disparities Research and Workforce Diversity conducted a <u>webinar</u> in September 2021 titled "Advancing Evidence-Based Interventions to Improve Access to Mental Health Services for LGBTQ+ Youth." More than 420 people participated in this webinar.

SGMRO staff members continued to present virtually at intramural and extramural venues on the work of the Office, NIH-specific grantspersonship, salient issues in SGM health and research, and SGM-related work being conducted at the agency. FY 2021 presentations are listed below.

#### Presentations to NIH and Other Government Organizations

- DPCPSI Deputy Directors
- Equity and Justice Roundtable on Healthcare—Office of Congressman David Trone
- National Institute of Neurological Disorders and Stroke (NINDS) Health Equity Workgroup
- NIH Amgen Scholars Program
- NIH Common Data Elements Task Force
- NIH Communications Directors Meeting
- NIH Inclusion Governance Committee
- NIH Management Directive-715 Points of Contact
- NIH Planning and Evaluation Officers' Meeting
- NIH Policy Webinar Related to 2020 NASEM Report
- NIH Postdoctoral and Clinical Fellows
- NIH Stakeholder Engagement in the Era of COVID-19 and Social Justice Movements Priorities for FY 2021
- NIH Training Center
- ODP's Prevention Research Coordinating Committee
- Office of Research Infrastructure Programs
- Office of the Executive Secretariat Staff Meeting
- OITE Health Science, Communications, and Policy Virtual Program
- SWD Office
- Stigma Research Training Institute
- Trans-NIH Measurement Coordination Group

#### Presentations at Extramural Institutions, Conferences, and Other Research-Related Settings

- 9th Annual LGBT Health Workforce Conference
- Alzheimer's Association's Strategic Focus Meeting on LGBTQIA+ Populations and Dementia
- ATN
- Bio Ascend
- Columbia University LGBT Program
- Fenway Institute and Harvard Sexual Orientation and Gender Identity and Expression Health Equity Research Collaborative
- The George Washington University
- Harvard Medicine School Sex- and Gender-Informed Medicine course
- Hauser Policy Lecture: Advancing the Well-Being of LGBTQI+ Populations
- National Academies' Webinar Series on Advancing the Well-Being of LGBTQI+ Populations
- National LGBTQ Health Conference
- National Organization of Gay and Lesbian Scientists and Technical Professionals
- Rainbow Research Group Grant Writing Workshop for Early Career Scholars of the Gerontological Society of America
- SAGE Publishing and the Federation of Associations in Behavioral & Brain Sciences
- SGM Health Working Group Meeting of the ECOG-ACRIN Cancer Research Group
- Society for Prevention Research Virtual 29th Annual Meeting
- U.S. Conference on HIV/AIDS
- University of California, San Francisco Center for Sexual & Gender Minority Health Grand Rounds
- University of Nevada
- The University of North Carolina at Chapel Hill CFAR
- The University of Texas at Austin Pride Health Pop-Up Institute
- Vanderbilt University
- Whitman-Walker Institute

# **Goal Three**

Foster a Highly Skilled and Diverse Workforce in SGM Health Research

#### **REMOVING BARRIERS TO EQUITY IN THE WORKFORCE**

The NIH administers a variety of collaborations that seek to eliminate racism, harassment, and discrimination, and to further diversity, equity, inclusion, and accessibility (DEIA). In February 2021, the NIH launched the <u>UNITE</u> initiative to root out and address structural racism and racial inequities throughout the biomedical, clinical, behavioral, and social sciences research enterprise. As part of UNITE, the NIH established the Anti-Racism Steering Committee (ARSC) to promote racial and ethnic equity across the agency, remove barriers to professional growth for staff from diverse backgrounds and underrepresented groups, and help guide internal policy considerations. SGMRO staff participate in the ARSC Trainee Subcommittee to assist in promoting equity and removing barriers for NIH trainees.

The NIH OD Anti-Harassment Champions Working Group was established to help the OD serve as a model for anti-harassment efforts at the NIH. In FY 2021, the group established August as OD Civility Month. This celebration was a part of the NIH's larger mission and commitment to address and mitigate harassment and incivility in the workplace. Highlights of the month's activities included a town hall with NIH leadership and a scientific seminar. The SGMRO Director is the co-chair of this OD-wide effort. The SGMRO Director also continues to serve on the NIH Anti-Harassment Steering Committee. This NIH-wide committee promotes a culture where harassment is not tolerated at the agency. In FY 2021, an additional SGMRO staff member joined the steering committee.

Representatives from the SGMRO, OEDI, and NIH's Office of Budget participate in the White House Interagency Working Group on Safety, Opportunity, and Inclusion for Transgender and Gender Diverse Individuals. The working group is charged with leading a coordinated federal approach to address the root causes of discrimination, barriers to economic opportunity, and stigma that genderdiverse people continue to face. As part of the working group, the White House convened a series of listening sessions for agency participants to hear directly from transgender individuals and advocates with professional or personal expertise on issues related to violence and economic opportunity. Outcomes of group activities included a <u>report</u> highlighting priorities brought to the fore during the listening sessions and commitments from agencies to move forward key opportunities in this area. The former Chief Officer for Scientific Workforce Diversity (COSWD), Dr. Hannah Valantine, and former NIH Director, Dr. Francis Collins, invited ICOs to nominate representatives to become NIH <u>Diversity Catalysts</u> in 2014. These individuals were tapped to inform and enhance DEIA efforts throughout the agency using personal and IC-specific expertise and experience. The SGMRO continued to serve as a Diversity Catalyst in FY 2021. As of the end of FY 2021, the Diversity Catalysts were working to adopt two tools from the <u>NIH Scientific Workforce Diversity Toolkit</u> at their own ICOs: (1) a <u>workforce recruitment search protocol</u> to identify qualified scientific researchers from diverse backgrounds; and (2) an <u>implicit bias education module</u> to help NIH staff and other professionals learn what implicit bias is, how to recognize it, and how to minimize its impact so that the NIH can continue to foster a culture of inclusive excellence.

SGMRO staff also sit on the DPCPSI Working Group to Promote Social Justice. This working group is charged with identifying Division employee needs, stimulating and facilitating communications, and developing strategies and activities to promote social justice and equity in the workplace. The Working Group was established in FY 2020, and its membership was expanded by the DPCPSI Director in May 2021. In FY 2021, facilitated discussions were held to build trust and identify pertinent opportunities, goals, and activities to foster social justice Division-wide.

The SGMRO Director retains *ex officio* membership on the NIH Advisory Committee to the Director's (ACD) Working Group on Diversity (WGD). The WGD is charged with assisting the ACD in developing effective diversity-related strategies for NIH. This includes enhancing access and opportunities for all members of the health research workforce, including scientific and support staff. The group also informs policy and procedural changes needed to enhance personal and institutional accountability for upholding DEIA principles. The ACD WGD maintains SGM-related representation from the extramural community. The charge of the working group expanded in FY 2021 to include providing suggestions about the scope of the areas that the NIH UNITE initiative covers.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Office of the Director established the NIDDK Inclusion, Diversity, Equity, Accessibility, and Civility Steering Committee to develop a strategic framework for a diverse, inclusive, and respectful workplace. After soliciting Institute staff for ideas on which areas the committee should work to address, the committee launched the LGBTQ+ Community Support Working Group. This group created several products in FY 2021, including multiple NIDDK-wide email messages in support of the LGBTQ+ workforce and promotion of the inclusion of pronouns in email signatures, Pride Month graphics and Zoom background templates, and an IdeaScale survey to ask the broader NIDDK community for input on the current climate for employees who identify as LGBTQ+ individuals and potential actions for support, such as promoting allyship.

Salutaris: The NIH SGM Employee Resource Group (ERG) was reinvigorated throughout FYs 2020 and 2021. The ERG serves as a platform for NIH employees who identify as LGBTQI+ and their allies to discuss issues specifically affecting the LGBTQI+ community within and outside of the agency, to connect with one another, and to develop strategies to increase and improve recognition of SGM employee viewpoints and needs. Event highlights in FY 2021 included meetings with the Principal Deputy Director of the NIH, the SGMRO Director, and members of the UNITE Initiative's U Committee for understanding stakeholder experiences; interactive discussions on the professional and personal trajectories of numerous Salutaris members; and regular assemblies for more casual interaction and community-building. Members of the SGMRO, NIDDK, and OEDI, all of which are members

of Salutaris, continued to participate in Pride in Federal Service (PFS). PFS is a federal interagency community of practice focused on inclusion and consideration of sexual orientation and gender identity (SOGI) in federal employment and supports a broad array of federal LGBTQ+ ERGs.

#### **EDUCATION**

NIH personnel conduct training, give presentations, and share resources and experiences to support people who identify as LGBTQI+ in the internal and external SGM health research workforces and the LGBTQI+ community at large. OEDI utilizes <u>Safe Zone</u> trainings to promote awareness and education within the NIH community regarding the needs and concerns of SGM employees, contractors, interns, and trainees. These interactive sessions promote an atmosphere of openness and safety at the agency by providing key information necessary to address many commonly held misconceptions, myths, and stereotypes about SGM people and offering opportunities to ask questions, receive feedback, and hone the skills necessary to address issues in the workplace as they arise. In FY 2021, OEDI held three *Safe Zone* training sessions. In addition, OEDI worked with HRSA's Office of Civil Rights, Diversity, and Inclusion to create and co-present a HRSA-specific adaptation of *Safe Zone* in September 2021 that focused on creating safe spaces and supporting the HRSA LGBTQ+ workforce.

The NIH Office of Research Services offered a webinar entitled "Honoring Diversity: Ensuring Equity and Inclusion for LGBTQ Individuals" led by the Federal Employment Law Training Group. During this virtual training, attendees learned how to comply with relevant Executive Orders, ensure that legal protections for transgender employees are respected, identify and respond to acts of microaggression against LGBTQI+ employees in the workplace, better understand implicit bias, and recognize and define harassment.

A training segment called "Sexual and Gender Minorities Research at NIDDK" was featured as part of the Health Disparities Research Module for the NIDDK Extramural Staff Training. The training included relevant background and definitions; a description of the SGMRO, its activities, and its Research Coordinating Committee (SGM RCC); the importance of SGM research and funding opportunities; highlights of both the NIH and the NIDDK-specific SGM Portfolio Analyses; SGM health and employee resources at the agency; and a live question and answer session that took place in February 2021.

OITE led the <u>Diversity and Inclusion Seminar Series</u> in FY 2021. The series consisted of interactive webinars and small-group discussions intended to build understanding of the role that everyone can play in supporting equitable access to valuable societal resources and advancing relevant and necessary health care research while also exploring participants' personal experiences and unconscious biases. The goal of the series was to help attendees become better allies and advocates for diversity and inclusion within their workplaces, neighborhoods, and the broader science community. The seminars were geared toward postbaccalaureate and graduate students and postdoctoral fellows, and covered a broad swath of topics, including diversity and inclusion in a multicultural society, the science of diversity, building belonging in a time of othering, and reflecting on biases. Sex, SOGI, and SGM populations were considered and discussed throughout the series.

OEDI coordinated the FY 2021 NIH Pride campaign <u>Using Pronouns to Demonstrate Allyship</u> in June. The campaign expanded on a larger exploration happening within NIH of the vital role and responsibility of <u>allies</u> and how to leverage allyship in promoting inclusivity in both the workforce and in health. The campaign offered pronoun usage as one of the many ways to demonstrate support

for SGM individuals. FY 2021 Pride projects included a downloadable infographic titled "What Are Pronouns?"; updates to the OEDI's Sexual and Gender Minorities Terminology and Pronouns Resources webpages; and the blogs "LGBT—What's the Difference?," "What Are Gender Pronouns?" Why Do They Matter?," and "LGBT Labels and Safe(-r) Language."

In addition to these resources, OEDI held multiple Pride events with collaborators across the NIH. OEDI teamed up with the SGMRO to host a Twitter chat and diversity expert-moderated discussion on how to better use pronouns for more effective allyship. NIDCD, NIDDK, and the National Center for Advancing Translational Sciences (NCATS) participated in this chat. OEDI, in conjunction with Salutaris, hosted a virtual lecture on work-related disparities and barriers experienced by LGBTQ scientists in the U.S. workforce. The National Institute of Environmental Health Sciences (NIEHS), as part of its Office of Science Education & Diversity Speaker Series, co-hosted an SGM panel with OEDI featuring discussants from OEDI, NCI, NHGRI, NHLBI, OBSSR, and the National Institute of Dental and Craniofacial Research. This panel afforded members of diverse communities under the LGBTQ+ umbrella the opportunity to speak about their experiences at the NIH, their efforts to increase diversity in the NIH workplace, how the NIH has changed over time around LGBTQ+ issues, and what their communities hope for in the future.

The NHGRI Inter-Society Coordinating Committee for Practitioner Education in Genomics has a Project Group focused on LGBTQI+ Issues in Genomics Education. The Project Group seeks to create an evidence base and educational materials to (1) increase awareness of LGBTQI+ and other sexual and gender diverse identities, populations, and needs among the genomic medicine and genomics education workforce; and (2) engage LGBTQI+ community members in understanding, informing, and benefiting from genomic medicine and genomics education. The Group works to increase partnerships between LGBTQI+ and other SGD people to create an engaged and aware genomics workforce, to remove barriers to testing and care for LGBTQI+ people, and to serve LGBTQI+ people with the highest standards of cultural humility and clinical competence.

In response to issues illuminated by the extramural research community, the SGMRO and NICHD spearheaded the development of a resource on practicing cultural competency in personal and professional communications involving sex and gender. This resource was created with a subcommittee comprising Fogarty, NCATS, NIEHS, ODP, ORWH, and the Office of Data Science Strategy. Further feedback and recommendations were incorporated after presentation of the resource to the OEDI, ORWH, Salutaris, SGM RCC, SWD, the Center for Scientific Review, and the SGM Research Working Group (RWG). This resource is intended to summarize key issues related to sex, gender, and gender identity in language; help participants develop competence and sensitivity toward gender-related issues in everyday interactions; and generally encourage more respect and professionalism in interactions among people working at the NIH and between NIH staff and the extramural community. Plans are underway to expand the availability of the resource in 2022.

#### **CONNECTING WITH RESEARCHERS**

The NIH supported multiple activities to foster the success of researchers interested or currently active in the field of SGM health research. The SGMRO signed on to the National Institute of General Medical Sciences–administered Maximizing Opportunities for Scientific and Academic Independent Careers (MOSAIC) Institutionally Focused Research Education Award to Promote Diversity in an effort to encourage SGM representation in the program. Ten ICOs participated in the FY 2021 round of the program. MOSAIC supports courses for skills development and mentorship activities to help inspire

and prepare postdoctoral and early-career scholars who are underrepresented in health research to successfully transition into or continue pursuing studies or careers in research.

Fogarty coordinated and executed the Stigma Research Training Institute (SRTI) in June 2021. The SRTI consisted of two weeks of didactic, panel discussion, and small-group sessions, as well as opportunities to interact directly with trained stigma researchers. The Institute provided 51 early-to mid-career investigators from the United States and abroad with knowledge and resources to enhance their capacity to address stigma research questions. During the Institute, scholars learned about the NIH grant process, stigma research funding opportunities at the agency, pertinent theories and frameworks, methods and measurement, research designs and approaches, interventions, policy development, and ethical challenges. SGM-specific experiences with stigma and related research and strategies were discussed at several points during the SRTI, including in presentations on SGMRO interests in stigma research, intersectionality and stigma, and the use of an intersectional stigma reduction intervention to improve HIV testing in MSM. The SGMRO and various other ICOs participated in all aspects of the SRTI, from the steering committee and applicant review to serving as panelists and contributing to the final report out.

In August 2021, NIMHD convened the sixth annual Health Disparities Research Institute (HDRI). 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. Sixty-two individuals participated in the virtual meeting. SGM-relevant areas covered during the FY 2021 HDRI included the etiology of health disparities, methods and measurement, and intervention and implementation research. Institute attendees received consultation on developing research interests, learned about NIH application submission and review processes, took part in a mock grant review, and received information about health disparities resources and programs at the NIH, all of which were intended to help participants develop and submit successful grant applications. The SGMRO and program officials representing ICOs across the agency also participated in meet-and-greet sessions where scholars were able to inquire about specific research questions and forge new collaborations.

OITE, in partnership with the Foundation for the NIH and the Amgen Foundation, coordinates the <u>Amgen Scholars Program at NIH</u>. This program is for undergraduates interested in learning more about health disparities and the role that science, policy, and community engagement can play in their elimination. The program has four core components: (1) independent research performed under the mentorship of an NIH intramural scientist, (2) roundtable discussions exploring the intersection of research and public policy related to health disparities, (3) career guidance and mentorship focused on a broad array of biomedical careers, and (4) leadership training focused on the skills needed to successfully work in team-oriented global research environments. An SGMRO staff member served as a mentor to two Amgen Scholars in FY 2021.

In a September 2021 <u>blog post</u>, the SGMRO Director was interviewed by the COSWD on the subjects of the mission and activities of the Office, implementation of the FYs 2021–2025 NIH SGM Health Research Strategic Plan, and the role of the SGMRO in creating a more diverse and inclusive health research workforce.

The SGMRO team continues to assist current and potential SGM health investigators in submitting the best applications possible by helping them to determine the most appropriate FOAs, funding mechanisms, and administering ICs for their work. The SGMRO also offers feedback on the relevance and impact of proposed research in the context of the current NIH SGM research portfolio.

The SGMRO continues to furnish technical assistance and expertise to NIH personnel concerning SGM-specific needs, considerations, and language in various initiatives, collaborations, FOAs, grant reviews, and other activities. Extramural program officers at NIH ICOs continue to offer technical assistance to current and potential investigators interested in SGM health-related research by providing recommendations for aligning applications with ICO-specific priorities across a variety of relevant research areas.

#### **OTHER GOAL THREE-RELATED ACTIVITIES**

In line with the June 2021 Executive Order on Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce, the NIH established a workgroup to develop the agency's first DEIA Strategic Plan. The SWD Office, OEDI, DPCPSI, and the NIH Office of Human Resources have engaged personnel from ICOs (including the SGMRO) and DEIA-related committees and communities at the NIH to draft the plan and collect internal and external input. The plan, when developed, will delineate goals and provide a framework for activity and program implementation to enhance DEIA at the NIH.

The SGMRO held five webinars in FY 2021 as part of its ongoing <u>Scientific Webinar Series</u>. The series gives a platform to investigators conducting current and groundbreaking SGM health research to discuss their work and career trajectories and provides a forum that allows students, postdoctoral fellows, early-stage investigators, and others to envision a career in SGM health research. Topics examined during the FY 2021 series were sexual and reproductive health research design, the impact and mitigation of historical trauma among Two-Spirit American Indians and Alaska Natives, discrimination and mental health among sexual minority individuals, inclusion of deaf and hard-of-hearing sexual and gender minorities in research, and minority stress and the health of transgender persons.

The <u>SGM Health Researcher Spotlight</u> featured four researchers in FY 2021. These spotlights engage successful early and established NIH-funded investigators working in SGM health research in an interview format to explore pathways to and provide guidance for building a successful career in the field. FY 2021 interviewees have research foci in intersectional and structural stigma as drivers of LGBTQ health disparities, intersectionality in risk and protective factors for SGM health, variability in health disparities among SGM populations, gender identity– or expression-based discrimination among transgender people, and the cancer continuum among gender minority adults.

The fourth annual <u>NIH SGM Research Investigator Awards Program</u> took place in September 2021. The program honored two Early-Stage Investigators and a more established Distinguished Investigator for their considerable and exceptional work in fields related to SGM health and well-being. Awardees were invited to present on their research programs during the virtual ceremony.

The SGMRO also expanded to eight members in FY 2021. This expansion enriched the expertise and experience of the Office and significantly augmented the Office's capacity to fulfill the goals of the FYs 2021–2025 NIH SGM Health Research Strategic Plan.

# **Goal Four**

Encourage Data Collection Related to SGM Populations in Research and the Health Research Workforce

The NIH worked to promote, increase, and enhance collection and usage of data on SOGI and sex (including intersex status) through a variety of efforts in FY 2021. In FY 2021, SGMRO released the FY 2019 SGM Research Portfolio Analysis, which summarizes key data on NIH-wide research investments in SGM health in a given fiscal year. This document also illuminates areas that need additional research in the NIH-wide SGM research portfolio for consideration by investigators and other interested parties. In accordance with the recommendation made by the SGM RWG in its Mid-Course Strategic Plan Review, the FY 2019 analysis entailed a rigorous assessment of the SGM research portfolio. Similar to the FY 2018 analysis, the FY 2019 analysis included curation of projects by race, ethnicity, SGM subpopulation, age group, and certain social categories, as well as by research methods employed, category of research, and specific special topics. In addition to the primary analysis, the SGMRO published snapshots that drilled down into the NIH-wide research portfolios on specific SGM groups, namely people who have a difference of sex development (DSD) or identify as intersex, transgender persons, and bisexual individuals. According to NIH <u>RePORTER</u>, 500 SGM projects were funded by 21 ICOs in FY 2020; this represents a 66.1 percent increase in SGM research project support by the NIH between FYs 2015 and 2020.

The Healthy People (HP) initiative identifies public health objectives and priorities to help individuals, organizations, and communities across the United States improve health and well-being. New foci and goal sets are established every decade to align with the greatest health issues facing the American people, and trends for critical health measures from prior decades are also maintained. HP helps users access data on changes in the health status of the U.S. population, including LGBT people. In Healthy People 2030 (HP2030), the fifth iteration of HP, the LGBT Health topic area has been expanded to 13 measurable objectives and three developmental objectives that span student bullying, usage of illicit drugs, suicidality, sexually transmitted infections, and collection of data on SOGI and SGM populations in national surveys. HP allows additional objectives to be added throughout the decade to reflect emerging or critical developments in any given area, so these objectives may be expanded at a later time. The SGMRO provides review and guidance as needed to the Healthy People 2030 LGBT Health Topic Area Workgroup, a subset of the larger Healthy People 2030 Federal Interagency Working Group. The ODP and the HHS Office of Disease Prevention and Health Promotion are co-funding two activities related to the HP2030 LGBT

objectives: (1) building the foundation of HP2030 data visualization and disparities measurement and (2) implementation and dissemination of evidence-based resources to achieve the HP2030 goals and objectives.

The National Center for Science and Engineering Statistics (NCSES) within the National Science Foundation issued a Broad Agency Announcement to provide opportunities to conduct collaborative research projects with the Center. NCSES and the NIH support RAND Corporation and the University of Alabama at Birmingham, which are conducting a qualitative study titled "SOGI @ Work: Current State of Measuring SOGI in the Workplace." SOGI @ Work will deepen our understanding of the SOGI data collected by employers across multiple sectors (e.g., public, private, academic, nonprofit) with a focus on fields in science, technology, engineering, and mathematics (STEM). The study will seek to answer questions concerning the current state of SOGI data collection in STEM industries, measures currently used, adequacy of data collection, data usage, and identification of plans to change data collection paradigms if they exist.

During the development of its report on understanding the well-being of LGBTQI+ populations, NASEM recognized the need for improved and novel measures that more accurately capture the full lived experiences of SGD people, including the range of sexual and gender diversity and determinants of well-being for SGD populations. In response to this, the SGMRO and 18 other components<sup>4</sup> of the NIH commissioned the NASEM to develop a <u>consensus report</u> on guiding principles and standard measures for collecting data on sex and SOGI in research, clinical, and administrative settings. The members of the report panel were announced in April 2021; the report panel subsequently held open meetings to hear from outside subject matter experts and closed meetings to discuss report content, details, and recommendations.

The agency participates in various groups that focus on SGM data collection and policies. The SGMRO is represented on the HHS Data Council within the Office of the Assistant Secretary for Planning and Evaluation. The council guides and informs HHS-wide data policy, including the development and implementation of an HHS data strategy, data standards, and privacy policies. Members of the SGMRO and the NICHD participate and hold leadership roles in the Measuring SOGI Research Group of the Federal Committee on Statistical Methodology (FCSM). This interagency group explores best practices for precise, accurate, and rigorous SOGI measurement in the context of federal information collection efforts with specific foci in youth, proxy reporting, and terminology. Co-chairs and members of the FCSM Measuring SOGI Research Group provided technical assistance in FY 2021 on the inclusion of SOGI questions in national surveys to various federal agencies in the form of relevant background information and input and recommendations on language and content. In June 2021, the research group published a brief exploring the importance of asking SOGI questions in federal surveys and describing efforts to develop effective SOGI questions.

The SGMRO was invited by the Office of Management and Budget to participate in the Interagency Technical Working Group (ITWG) on inclusion of SOGI questions in the U.S. Census Bureau's Household Pulse Survey (HPS), which longitudinally gauges the socioeconomic and general household impacts of the coronavirus pandemic nationwide. In April 2021, the ITWG released consensus recommendations for SOGI items in the HPS, which were subsequently deployed beginning in July 2021. Following the fourth and final cycle of HPS SOGI data collection in

<sup>&</sup>lt;sup>4</sup> This consensus study was also co-funded by *All of Us*, NCI, NHGRI, NIA, NIAID, NICHD, NIEHS, NIMH, NIMHD, NINDS, OAR, OBSSR, ODP, OEDI, OITE, ORWH, SWD, and the Office of Strategic Coordination.

September 2021, associated <u>analyses</u> were published documenting significantly higher rates of economic and mental health hardships for LGBT people during the COVID-19 pandemic. The ITWG is charged with designing a plan for monitoring, testing, and revising any SOGI questions added to the HPS.

The NIH actively supports data sharing and analysis of existing data on SGM health and experiences. NICHD, along with OBSSR and ORWH, supports two major SGM population studies that recently released their data sets to the general public: <u>Generations</u> and <u>TransPop</u>. Generations is a 5-year study examining identity, stress, health outcomes, and health care and services utilization among lesbian, gay, and bisexual adults who came of age in three different generations and historical contexts. The U.S. Transgender Population Health Survey, also known as TransPop, comprises the first national probability sample of transgender individuals in the United States. The study aims to provide information about transgender population demographics, basic health outcomes and health behaviors, and experiences with discrimination, identity history, and transition.

*All of Us* continues to collect self-reported data on SOGI and sex (including intersex status) from participants in its <u>Basics Survey</u> in service of its mission to build a robust research resource that can facilitate the exploration of biological, clinical, social, and environmental determinants of health and disease. *All of Us* will collect and curate health-related data and biospecimens from 1 million or more individuals who reflect the diversity of the United States; these data and specimens will be made broadly available for usage in research. Currently, *All of Us* data can be accessed publicly through the <u>Data Browser</u> and through the Researcher Workbench for program-approved investigators.

The NIH encourages the use of common data elements (CDEs)<sup>5</sup> in clinical research, patient registries, and other human subject research in order to increase and enhance opportunities for comparison and combination of data from multiple studies and with electronic health records. The usage of CDEs represents an important opportunity to improve data quality, usability, and interoperability for SGM research studies, surveys, and other data collection efforts. The <u>NIH CDE Repository</u> houses CDEs for inquiring about SOGI, sex assigned at birth, and SGM-relevant social determinants of health (SDOH). Of relevance, SGMRO is represented on the NIH CDE Task Force, which has broad representation from NIH ICOs and HHS agencies and seeks to improve the communication and coordination of efforts to develop and promote the use of CDEs for clinical and other human subjects research. The SGMRO and numerous ICOs also sit on the CDE Task Force's Working Group on SDOH.

The PhenX Toolkit, supported by NHGRI and several other ICOs, furnishes measurement protocols that contain the same elements as CDEs. In October 2020, NIMHD issued a Notice Announcing Availability of Data Harmonization Tools for SDOH via the PhenX Toolkit with participation from seven other ICOs, including the SGMRO. This notice highlights and encourages the incorporation of measures in the Toolkit's SDOH Core and Specialty collections whenever feasible. Both collections feature SGM-relevant measures. Of particular interest are the core collection protocols for capturing data on biological sex assigned at birth and SOGI; these protocols are designated relevant and essential to all areas of minority health and health disparities research, and investigators are strongly encouraged to incorporate these measures in all primary data collection.

<sup>&</sup>lt;sup>5</sup> A CDE is a fixed representation of a variable comprising one defined question paired with a specified set of allowable responses that are used in common across multiple studies, research sites, initiatives, or data sets.

## **Closing Thoughts**

Although 2021 was a year with considerable trials, it was also a year in which substantial progress was made at the NIH in promoting research for members of the SGM community through resolute support of research and funding opportunities, extensive cooperation, continual workforce development, and expanded data collection. As is illustrated by the expansive range of SGM-focused activities and accomplishments found in the FY 2020 Annual Report, as well as previous Annual Reports, SGM health research continues to gain momentum as a field of high import within and outside of the agency. By allying with and working tirelessly alongside experts and interested individuals in the public, private, and academic sectors and the SGM and SGM advocacy communities, the NIH continues to set in motion and champion efforts to help bring about health equity for SGM people.

