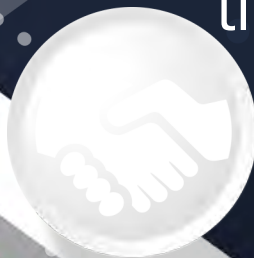


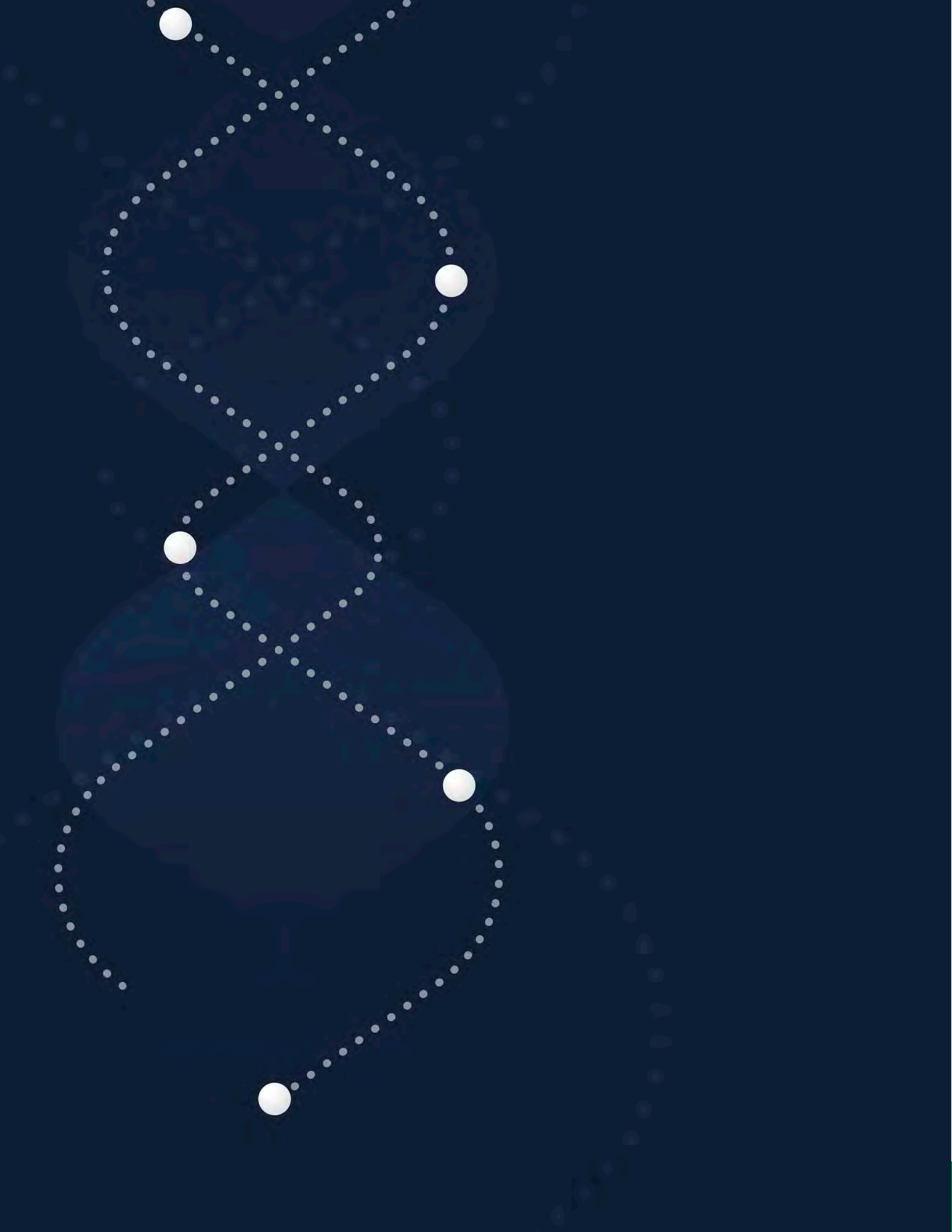
Sexual & Gender Minority
Research Working Group
of the NIH Council of Councils

Mid-Course Review of
the NIH Strategic Plan
to Advance Research on
the Health and Well-being
of Sexual & Gender
Minorities

Convened on
September 7, 2022



National Institutes of Health
Sexual & Gender Minority Research Office



INTRODUCTION

The [Sexual & Gender Minority Research Office \(SGMRO\)](#) coordinates sexual and gender minority (SGM) health research activities across the National Institutes of Health (NIH); represents NIH at conferences and events focused on SGM research; serves as a resource regarding SGM-related research activities for the extramural and NIH communities; connects extramural researchers with key NIH contacts; convenes conferences and workshops to inform priority-setting and research activities; collaborates with NIH institutes, centers, and offices (ICOs) on the development of SGM health research reports; leads the implementation of the [NIH Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities: Fiscal Years 2021–2025](#); and leverages resources to develop initiatives to support SGM health research.

Funding for SGM research at NIH has been increasing steadily since 2015, when SGM projects were first able to be systematically identified. In fiscal year 2021 (FY21), 546 SGM-related projects were funded, which is an 81.4 percent increase from the 301 projects funded in fiscal year 2015 (FY15). In comparison, the [total number of projects at NIH increased](#) from 51,382 in FY15 to 63,649 in FY21, an increase of 23.9 percent. The total for the HIV/AIDS component of funded SGM-related projects for FY21 was 55.5 percent, a decrease from 73 percent in FY15, indicating a portfolio that is more balanced in scope and topic. SGMRO works to encourage researchers to apply for SGM-related research funding in areas that need additional studies. About 60 percent of SGM-related research projects are funded through research (R) mechanisms, and additional applications are being funded under career (K) and fellowship (F) mechanisms.

NIH STRATEGIC PLAN TO ADVANCE RESEARCH ON THE HEALTH AND WELL-BEING OF SEXUAL AND GENDER MINORITIES: FISCAL YEARS 2021–2025 MID-COURSE REVIEW

The NIH Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities: Fiscal Years 2021–2025 highlighted five overarching considerations in SGM research: intersectionality, life situations, aging, SGM subpopulations, and relevant research strategies. The scientific themes and research opportunities were categorized under additional topics, including clinical research, social and behavioral research, research on chronic diseases and comorbidities, and methods and measurement research. The strategic plan laid out four operational strategic goals:

1. Advance rigorous research on the health of SGM populations in both the extramural and intramural research communities.
2. Expand SGM health research by fostering partnerships and collaborations with a strategic array of internal and external stakeholders.
3. Foster a highly skilled and diverse workforce in SGM health research.
4. Encourage data collection related to SGM populations in research and the health research workforce.

On September 7, 2022, the [SGM Research Working Group \(RWG\)](#) of the [NIH Council of Councils](#) convened to conduct a mid-course review of the strategic plan and evaluate progress on the goals of the plan and provide recommendations for capitalizing on this progress.

EXAMPLES OF PROGRESS MADE & RECOMMENDATIONS BY GOAL AREA



Goal 1: Advance rigorous research on the health of SGM populations in both the extramural and intramural research communities

EXAMPLES OF PROGRESS MADE

Objective 1: Develop scientific workshops to identify SGM research opportunities.

In FY21, SGMRO hosted a multiphase NIH Scientific Workshop on Violence and Related Health Outcomes in SGM Communities, resulting in a report highlighting research opportunities. SGMRO is co-funding a related journal supplement in [LGBT Health](#). Currently, SGMRO is planning the NIH Scientific Workshop on Expanding the Evidence Base in Gender-Affirming Care for Transgender and Gender-Diverse Populations, which will be held in March 2023. A [request for information](#) was issued, and listening sessions and working groups were convened prior to the main workshop. Three working groups will focus on pediatric and adolescent populations; adult and older adult populations; and systemic, institutional, and ethical policies. The main workshop will bring together experts to discuss the research opportunities and priorities identified by the working groups, and a report will be developed following the workshop.

Objective 2: Encourage ICOs to set SGM health-specific and relevant research as a priority.

SGMRO has led efforts and signed on to numerous funding opportunity announcements (FOAs) to encourage research relevant to SGM populations. FOAs include such topics as measurement, violence, and health disparities research. To date, the SGMRO Administrative Supplements Program has funded more than \$8 million across 86 unique supplements spanning a broad range of key topics in SGM health research. The office also published a notice of special interest (NOSI) regarding [Research on the Health of Bisexual and Bisexual+ People](#) to solicit research, research training, and research career development applications in response to SGMRO's 2019 scientific workshop on bisexual health.

Objective 3: Expand awareness of SGM-relevant research initiatives at the NIH.

SGMRO has authored and contributed to several publications related to SGM health research, including journal articles and book chapters, and has developed and published the [NIH SGM Health Disparities Research Framework](#). Staff also participate in many communications activities specific to research initiatives at NIH. The SGMRO webpage includes various resources, such as relevant

FOAs. The SGMRO Director and other SGMRO staff also present SGMRO and SGM-related research both at NIH meetings and at events with the extramural community.

Objective 4: Increase grant support for SGM health-specific research.

Preliminary data from the FY21 Portfolio Analysis demonstrate success in increasing grant support for SGM-related research, with an 81.4 percent increase in the number of projects between FY15 and FY21. This includes an almost 200 percent increase since FY15 in the number of non-HIV/AIDS-related research projects and an increase of more than 122 percent in the number of training and career awards granted. SGMRO is funding a summer internship enrichment program on SGM health disparities in the NIH Intramural Research Program (IRP), which will bring together summer interns and fellows interested in SGM health research.

GOAL 1 RECOMMENDATIONS FROM THE SEXUAL & GENDER MINORITY RESEARCH WORKING GROUP

1. NIH should provide funding to SGMRO for U54 Centers of Excellence in SGM health research.

The U54 FOA supported by the National Institute on Minority Health and Health Disparities required that funding be spread throughout the country, including among rural counties. This program could serve as a model for a similar program supported by SGMRO to increase research on SGM health across the country.

2. NIH should expand research on gender-affirming care for transgender and gender-diverse populations. NIH should increase funding to SGMRO to develop, along with partner ICOs, a network to research gender-affirming care and related health outcomes.

Many clinical sites conducting research on gender-affirming care lack scientific oversight, leadership, and support to ensure that research advances swiftly. NIH could develop networks or support research on important questions related to safety, models of care, and ethics on this important topic. A health equity lens is necessary to ensure that young transgender people from racial and ethnic minorities are included in this area of research. Networks should include community engagement, translational science, and local partnerships, and innovative approaches for network models should be encouraged. Urgency on this matter is particularly important given current trends in the incorrect, and often harmful, applications of science and medical expertise, which often are exacerbated by the lack of scientific and longitudinal information on transgender people. The Office of Research on Women's Health's [Building Interdisciplinary Research Careers in Women's Health \(BIRCWH\)](#) and the [Community Engagement Alliance \(CEAL\) Against COVID-19 Disparities](#) may serve as useful models.

3. NIH should increase education-related research via R25s focused on implementation and assessment to improve medical and allied health professional training related to LGBTQI+ health.

Better education on SGM issues for health care providers and their professional schools is necessary to increase awareness, visibility, action, and advocacy around SGM health. Although lack of comfort and knowledge around SGM topics on the part of health care providers is known to be the most significant barrier, methodologically based research on implementation or meaningful assessment of curriculum changes and outcomes is lacking.

4. NIH should identify SGM health-related research as a priority for the [Loan Repayment Programs](#).

Many young investigators are led to believe that SGM-related applications to the NIH Loan Repayment Programs have a lower chance of being funded. The SGM portfolio also needs to be emphasized across Loan Repayment Program mechanisms to ensure applicants understand that SGM populations are included and relevant across all research areas.



Goal 2: Expand SGM health research by fostering partnerships and collaborations with a strategic array of internal and external stakeholders

EXAMPLES OF PROGRESS MADE

Objective 1: Increase communications and training with ICOs and external stakeholders.

The SGMRO Director continues to serve as the co-executive director of the U.S. Department of Health and Human Services LGBTQI+ Coordinating Committee and works across the department to increase SGM research. She also co-chairs the Research and Data Subcommittee of this committee, and SGMRO staff participate broadly on numerous interagency committees, working groups, and task forces. SGMRO also has expanded its participation in NIH-wide steering committees, research coordinating committees, working groups, task forces, and employee resource groups.

Objective 2: Increase SGM expertise in NIH review panels and study sections.

SGMRO works with the [Center for Scientific Review \(CSR\)](#) to provide names of potential reviewers; SGMRO also promotes CSR's [Early Career Reviewer Program](#). SGMRO, the [Eunice Kennedy Shriver National Institute of Child Health and Human Development](#), and ICO staff have created print and web resources on gender-inclusive language, including the Culturally Competent Gender-Related Communications training module, which provides an overview of relevant concepts, outlines how to communicate respectfully with people in various roles, and emphasizes the importance of gender-neutral communication in reviews. This new resource may prove useful to CSR and institute and center (IC) scientific review officers and researchers participating in review panels and study sections.

Objective 3: Encourage cultural competency training opportunities on the specific characteristics of SGM health research for NIH-funded extramural and intramural clinical trainees and researchers.

SGMRO collaborated with the [Office of Intramural Training & Education \(OITE\)](#) and the Office of AIDS Research to develop and coordinate content for [Intramural Research Program](#) trainees for the [Health Science Communications and Policy Program](#) and the [NIH Academy on Health Disparities](#). SGMRO also launched the [NIH SGM Health Scientific Interest Group](#), which attracts many participants at various career levels across the country. These initiatives work to increase knowledge on the unique characteristics of SGM-related research and NIH grantspersonship.

GOAL 2 RECOMMENDATIONS FROM THE SEXUAL & GENDER MINORITY RESEARCH WORKING GROUP

1. NIH should enhance collaboration with the Agency for Healthcare Research and Quality (AHRQ) to identify ways to increase funding for health services research related to SGM health.

Many researchers contact SGMRO about research that is more aligned with the mission of AHRQ, but the small size of the agency makes arranging referrals challenging. Exploring additional capacities for collaboration with AHRQ could expand SGMRO's ability to support health services research related to SGM health.

2. SGMRO should collaborate with the [Office of Research on Women's Health \(ORWH\)](#) to update NIH-wide policies and external-facing educational materials to be more inclusive of sexual and gender diversity.

SGMRO is working with ORWH to publish a NOSI on testing gender-specific terms for measuring gender identity. Clinical trials inclusion enrollment tables should be updated to reflect current definitions of sex and gender.

3. SGMRO should continue to enhance collaborations with the Intramural Research Program and OITE.

SGMRO has been working to strengthen its partnership with OITE and support opportunities for trainees in the IRP. These collaborations could be enhanced to better support intramural research and training on SGM health.

4. SGMRO should continue to collaborate with CSR to encourage mentoring of early stage reviewers.

SGMRO currently promotes CSR's early career reviewer program, but these reviewers may hesitate to inform an expert review panel that it is using outdated or biased language or concepts. A mentoring component could be integrated into this program to increase the confidence of early career reviewers when participating in a review.



Goal 3: Foster a highly skilled and diverse workforce in SGM health research

EXAMPLES OF PROGRESS MADE

Objective 1: Develop resources and tools related to SGM health research for internal and external stakeholders.

SGMRO has undertaken numerous communications-related efforts, including adding content and tools to the SGMRO website, such as the Collaboration, SGM FOAs, Measurement, Research Resources, and Reports webpages. The office has developed training and resource materials on sexual orientation–inclusive and gender-inclusive language when working with LGBTQI+ people and SGM populations in research, clinical, and workplace settings. These materials include the resource [Gender Pronouns and Their Use in Workplace Communications](#). SGMRO staff also provided technical assistance on this topic to the NIH [Office of Communications and Public Liaison](#) on the [NIH Style Guide](#).

Objective 2: Continue to conduct regional workshops focused on building capacity in SGM health research.

SGMRO conducted a successful virtual [regional workshop](#) in Chicago in fiscal year 2022 and hosted a researcher event with NIH staff at the Society for Neuroscience’s [Neuroscience 2022](#) conference. Although the format of future regional workshops will depend on COVID-19 rates, feedback on past workshops has been positive.

Objective 3: Develop a grant mechanism to support institutional training efforts.

Although SGMRO continues to explore how to partner with the ICs to support a designated T32 grant, SGMRO staff have provided technical assistance for T32 grant applications, and one recent T32 grant has been funded.

Objective 4: Encourage the recruitment and retention of SGM researchers in the health research workforce.

SGMRO partnered with [NSF on the Broad Agency Announcement SOGI@Work](#) to better understand sexual orientation and gender identity (SOGI) data collection through systematic review and interviews with human resources departments. The availability of more data on SGM researchers in the scientific workforce would help improve the recruitment and retention of SGM researchers in the health sciences. NSF also works closely with the NIH Chief Officer of Scientific Workforce Diversity, who has communicated the need for SOGI data collection. Additionally, SGMRO funded a mentoring award focused on SGM health researchers in the field of substance use.

Objective 5: Collaborate with NIH training and workforce offices on SGM diversity issues to address the [NIH Workplace Climate and Harassment Survey](#) results concerning SGM populations to create a more welcoming environment.

SGMRO has strengthened its partnerships with the [NIH Intramural Research Program Training Directors](#) and NIH Academy on Health Disparities.

GOAL 3 RECOMMENDATIONS FROM THE SEXUAL & GENDER MINORITY RESEARCH WORKING GROUP

1. NIH should provide funding to SGMRO for T32 grants in SGM-related health research.

A T32 grant specifically designed to increase the health research workforce of SGM researchers could allow scarce resources to be utilized in creative ways. An R25-to-T32 path could reduce the number of LGBTQI+ students lost between undergraduate and graduate education. A multi-institution T32 grant could take advantage of the current familiarity with virtual work. The siloed nature of the NIH ICOs presents a challenge, particularly for aligning people engaged in SGM research across a variety of topics. Therefore, a T32 grant funded by SGMRO that works across ICOs could allow various topics to be studied while also encompassing the unique and overlapping issues related to SGM-specific research.

2. NIH should update its Notice of Interest in Diversity to explicitly include SGM populations.

The NIH [Notice of Interest in Diversity](#) includes a list of diverse populations, but SGM populations are not specifically named. Although the list is meant to be illustrative rather than exhaustive, ICOs have different interpretations of the notice. Explicit identification of SGM populations in the notice is critical for increasing diversity in the NIH-funded research community. SGMRO is working with the Office of Extramural Research to publish an FAQ to help clarify that SGM populations are included under the notice.

3. To conduct barrier analyses, NIH should collect SOGI data on principal investigators applying for funds.

Although NIH currently collects demographic data on applicants, SOGI data should be added to this routine data collection. Analyses of the SOGI demographics of applicants should be made public, just as other demographic analyses of applicants are.



Goal 4: Encourage data collection related to SGM populations in research and the health research workforce

EXAMPLES OF PROGRESS MADE.

Objective 1: Encourage the expansion of SOGI data collection and subsequent analyses in health care and related settings through such mechanisms as surveys, national data sets, and administrative data collection.

In 2020, SGMRO, along with 18 other components of NIH, commissioned the National Academies of Sciences, Engineering, and Medicine (NASEM) report on [Measuring Sex, Gender Identity, and Sexual Orientation for the NIH](#), which has led to significant communications about the recommendations. SGMRO serves as a resource for and provides technical assistance on SOGI data, and staff have delivered numerous presentations on the NASEM report to a variety of internal and external stakeholders, with additional presentations scheduled. SGMRO staff also participate in an interagency working group on SOGI data that was organized as a requirement of [Executive Order 14075](#), “Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals.”

Objective 2: Leverage existing data sets by engaging with ICOs and external organizations to collect SOGI data.

SGMRO continues to collaborate with the [All of Us Research Program](#), PhenX Social Determinants of Health Working Group, National Institute of Mental Health Common Data Elements Working Group, and National Cancer Institute Cancer Center Administrative Supplements Program to include SOGI collection measures.

Objective 3: Enhance SOGI-related data resources and data sharing, ensuring data privacy and security.

SGMRO launched a redesign of its [measurement website](#) to incorporate the NASEM recommendations and update existing content. Staff have contributed to Federal Committee on Statistical Methodology (FCSM) briefs and reports on SOGI measurement and data collection, including co-chairing the LGBTQI+ Data Equity Interagency Working Group action group on administrative guidelines for SOGI data collection, with recommendations to be included in the full report, The Federal Evidence Agenda on LGBTQI+ Equity.

GOAL 4 RECOMMENDATIONS FROM THE SEXUAL & GENDER MINORITY RESEARCH WORKING GROUP

- 1. Building on the research agenda set forth in the NIH-commissioned NASEM report on SOGI measurement, NIH should release FOAs, including administrative supplements, to fund more research on SGM health-related methods and measurement. This includes work on attraction and behavior, intersex status and variations in sex characteristics, and other key areas identified in the report.**

The NASEM report focused on measures of identity, but attraction and behavior also are key components of better understanding the health of SGM communities. The SGM RWG recommends advancing the measurement of attraction and behavior as distinct components of sexual orientation, which will help improve the understanding of many understudied identities, with a particular focus on moving beyond a binary framework.

- 2. The NIH Clinical Center should add sexual orientation and intersex status to its electronic health record system.**

The NIH Clinical Center (CC) currently collects gender identity information. SGMRO staff have been discussing the incorporation of NASEM's sexual orientation questions in NIH electronic medical records. CC staff likely do not ask the intersex status of every patient, but intersex status and sexual orientation should be collected as standard data items to further SGM research and enhance affirming care in the IRP.

- 3. SGMRO should collaborate with ORWH and the [National Library of Medicine](#) on guidance related to the collection, analysis, and reporting of sex and gender in journals.**

SGMRO should work with ORWH and the National Library of Medicine to communicate to journals the importance of collecting and reporting data on sex and gender, the difference between the two constructs, and how to incorporate other SGM-specific data, such as intersex status, which may be difficult to implement among people less familiar with health research.

- 4. SGMRO should work with colleagues via the FCSM SOGI research group to develop a primer on measurement science.**

A significant component of the education SGMRO has been providing on the NASEM recommendations is helping people better understand that measurement is a science. The recommendations in the report are based on standards and evidence. Respondents need to understand the questions to respond in a way that leads to accurate results. This will require education to ensure data collected align with researchers' intent. A primer on measures and methods related to SOGI measurement will increase researchers' ability to collect evidence-based data.

CONCLUSION

Although much progress has been made since the release of the *NIH Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities: Fiscal Years 2021–2025*, efforts at NIH related to SGM health research can be expanded. The SGM RWG of the Council of Councils anticipates that implementing the recommendations included in this report will yield additional progress across the four goals of the Strategic Plan.

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