

Sexual & Gender Minority Research Working Group

A Working Group of the
Council of Councils

Mid-Course Strategic Plan Review



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National Institutes of Health
Sexual and Gender Minority Research Office

INTRODUCTION

Since its creation in September 2015, the [Sexual & Gender Minority Research Office](#) (SGMRO) has worked to improve the health of sexual and gender minority (SGM)¹ populations through increased research and support of scientists conducting relevant research. The role of the SGMRO is to: coordinate SGM health research activities across the National Institutes of Health (NIH); represent the NIH at conferences and events on trans-NIH activities focused on SGM research; coordinate and convene conferences and workshops to inform priority setting and research activities; collaborate with NIH Institutes, Centers, and Offices (ICOs) on the development of SGM health research reports; manage information dissemination related to SGM research; and work with NIH ICOs to leverage resources and develop initiatives to support SGM health research. By coordinating directly with ICOs within the NIH, the SGMRO is poised to make a broad and sustainable impact across the agency.

In 2016, the NIH formed the Sexual and Gender Minority Research Working Group (SGMRWG) within the Council of Councils, a federal advisory committee. On September 5, 2018, the SGMRWG convened to conduct a mid-course review of the [NIH SGM Research Strategic Plan](#) and provide recommendations for consideration by the Council on ways that the NIH can support additional progress on each of the Plan's four goals through the second half of its term. The four goals of the Strategic Plan are as follows:

- 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 Plan focuses on fiscal years (FYs) 2016–2020 and includes goals and objectives relevant to work across the NIH. The SGMRWG concluded that the NIH has made initial progress in supporting SGM research and that the next step is to expand beyond this foundational success to provide further support to the many diverse subsets of the SGM portfolio.

¹ Sexual and gender minority (SGM) is an umbrella term utilized by the NIH 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. This includes individuals with disorders or differences of sex development (DSD), sometimes known as intersex.

GOAL ONE—Expand the knowledge base of SGM health and well-being through NIH-supported research.

The SGMRO's progress on Goal One to date includes supporting several SGM-specific funding opportunity announcements (FOAs) and convening the *Methods and Measurement in SGM Health Research Workshop* in April 2018. FOAs specific to SGM research are a signal to the research community that research involving SGM populations is critical and valued by the NIH. The SGM research portfolio at the NIH has been increasing steadily since FY 2015. In FY 2015, the NIH supported 301 SGM-related projects. In FY 2016, the number of projects increased to 334, and in FY 2017, 379 SGM-related projects were funded. Although the expansion of the portfolio should be recognized, it is important to note that not all research areas necessarily experience comparable increases in the projects funded (e.g., disorders or differences of sex development (DSD/intersex, bisexual, two-spirit). The most recent NIH SGM portfolio analyses ([FY 2015](#) and [FY 2016](#)) provide a more comprehensive picture of the SGM-funding landscape at the NIH.

The NIH also has implemented several strategies to improve the inclusion of SGM populations in research. The Clinical Center has begun to collect gender identity on patients in clinical research, and the National Institute on Minority Health and Health Disparities (NIMHD) has designated SGM populations as a health disparity population for research purposes.²

Recommendations From the SGMRWG

Publish FOAs focused on training the next generation of scholars through both individual and institutional awards (e.g., F, T, K, and R25 grants). Emphasize institutional awards, as the literature indicates that they can build capacity in less-developed research areas.³ Promote cross-institutional and interprofessional collaborations to facilitate research training in rare diseases.

Providing additional support and specific training for early stage investigators (ESIs), postdoctoral researchers, and others comprising the next generation of scholars is key to expanding the field of SGM research. In a community with little infrastructure, this critical stage in an investigator's career is an ideal time to expand the capacity and knowledge that young investigators need to succeed. This will create opportunities for these researchers to have an

² NIMHD. "Director's Message: Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes." October 6, 2016. www.nimhd.nih.gov/about/directors-corner/messages/message_10-06-16.html

³ Schwartz, A.L. "Physician-Scientist Career Awards and a Dilemma: National Institute of Child Health and Human Development K Awards—Individual, Institutional, or National?" *JAMA Pediatrics* 2018;172(3):218-219.

impact on the overall field of SGM research. Increased training can help researchers in this area work efficiently, develop mentoring and peer relationships, and assure people early in their development that they have a defined career path and that SGM research is valued by the NIH. Such institutional support can help combat the stigma and isolation often experienced by those in SGM research and may mitigate some of the disadvantages that SGM researchers may have in terms of mentorship and logistical support. Although much of SGM-related research focuses on HIV/AIDS, support for a wider variety of research disciplines is needed to address the diverse health needs of SGM populations. The NIH Office of Research on Women's Health's (ORWH) *Building Interdisciplinary Research Careers in Women's Health* program may serve as a model on how to provide SGM research training opportunities that are not specific to any particular disease area or health condition.

Release an FOA or Notice focused on SGM-related measurement, using outputs from the SGMRO-sponsored measurement workshop.

As a result of the growing need to develop better measures and methods to accurately capture and understand the health of SGM populations, in April 2018 the SGMRO brought together experts from a variety of fields to outline research opportunities in SGM-related methods and measurement. Research opportunities were highlighted under three areas: (1) measurement of SGM status; (2) measurement of related constructs; and (3) sampling methods. In many subsets of SGM health knowledge, baseline data are not available; researchers often struggle to receive funding without foundational data, yet these data cannot be collected without additional research and support. A specific call for SGM-related measurement research can help move the field of SGM research forward by increasing the understanding of the best measures and research methods to use.

Encourage all NIH applicants to demonstrate consideration of inclusion of SGM populations in clinical research, as appropriate.

The 21st Century Cures Act, signed into law on December 13, 2016, included SGM-specific provisions by amending the Public Health Service Act, SEC. 404N. [283] POPULATION FOCUSED RESEARCH.⁴ Those provisions are summarized as follows:

The Director of the National Institutes of Health shall, as appropriate, encourage efforts to improve research related to the health of sexual and gender minority populations, including by: facilitating increased participation of sexual and gender minority populations in clinical

⁴ Public Health Service Act, As Amended Through P.L. 115–302, Enacted December 11, 2018. <https://legcounsel.house.gov/Comps/PHSA-merged.pdf>.

research supported by the National Institutes of Health, and reporting on such participation, as applicable; facilitating the development of valid and reliable methods for research relevant to sexual and gender minority populations; and addressing methodological challenges.

Although SGM-specific research has increased over the last several years, many applications submitted to the NIH do not specifically mention SGM populations. Because required inclusion criteria do not pertain to SGM populations, it is difficult to determine a baseline for tracking the progress in SGM inclusion.

GOAL TWO—Remove barriers to planning, conducting, and reporting NIH-supported research on SGM health and well-being.

The SGMRO coordinates SGM-related research and other activities by working directly with the NIH ICOs. The establishment of the SGMRO fulfilled one objective under Goal Two; the SGMRO will continue to coordinate SGM-related work throughout the agency. The SGMRO has worked to facilitate communication between the extramural research community and the NIH community to encourage principal investigators to consider SGM-related research questions. In addition, the SGMRO serves as an internal resource for the NIH community on matters related to SGM research.

The October 2016 designation of SGM populations as a health disparity population for research has changed the interpretation of FOAs and the eligibility for the health disparities loan repayment program. In addition, the designation has helped legitimize SGM-related health research.

Recommendations From the SGMRWG

Publish a Notice in the *NIH Guide* to clarify the inclusion of SGM populations as a health disparity population for research funded by the NIH to ensure inclusion in related FOAs supported by the NIH.

Despite the designation of the SGM population as a health disparity population in October 2016, no standard language has been implemented to ensure that SGM populations are included in FOAs related to health disparities populations. When specific minority populations are listed, SGM populations should be included, and studies that do not list specific health disparity populations also should be expected to include SGM participants. However, communication about the policy has been inconsistent. There is a need for greater clarification among the research community, NIH program staff, peer reviewers, scientific review officers, and other NIH staff to ensure that the policy is implemented appropriately.

Expand the SGMRO to include one position for a scientist with program officer experience and one position for a communications specialist.

The SGM community is broad and diverse, requiring expertise in many areas and the logistical ability of the SGMRO to collaborate with many groups. As a coordinating office, the SGMRO participates in efforts across NIH ICOs; this collaboration is essential to ensuring that SGM-relevant research is considered across the agency. Additional staff members will improve the SGMRO's ability to meet more of its logistical needs and attend more meetings, workshops, and other relevant activities. A scientist with program officer experience will be able to offer insight into the NIH application process to improve the success of SGM-related applications and help connect principal investigators with appropriate program officers across the ICOs. A staff member dedicated to communications and outreach work will help expand the SGMRO's reach to improve the capacity of SGM researchers across the field.

Increase awareness of the SGMRO and SGM-related work at the NIH through targeted communications efforts, including social media and a Web presence.

A communications staff member within the SGMRO is needed to spearhead the expansion of information and knowledge under the diverse umbrella of SGM communities. The SGMRO has rich resources, but its dissemination ability has not been realized fully with the current resources of the Office. An increased social media presence for the SGMRO and an up-to-date and more informative website will help the SGMRO extend its coordination of efforts for researchers and trainees and other interested groups, particularly when interest increases after workshops, seminars, and presentations by the SGMRO Director. Increased communications could include newsletters or webinars to highlight researchers' experiences and work, which would help increase knowledge and capacity across the field and provide mentorship opportunities for ESIs and trainees.

Increase the SGMRO budget to provide funds for the training- and measurement-related FOAs recommended under Goal One.

The collaborative nature of SGM research requires that the SGMRO work across ICOs to support the training and measurement efforts that are required to expand the field. Because neither of these efforts falls squarely within the purview of another ICO, it is imperative that the SGMRO provide a financial commitment via co-funding to enable this work. As discussed, under Goal One, these FOAs will provide an opportunity to strengthen the community of scholars at a key point in their careers. This will expand and improve the overall field of SGM research and support research in all the diverse subsections and across all NIH ICO areas of research interest relevant to SGM populations.

GOAL THREE—Strengthen the community of researchers and scholars who conduct research relevant to SGM health and well-being.

After holding a successful and well-attended regional research seminar in May 2018, the SGMRO is moving forward with additional regional SGM research seminars in collaboration with local institutions. Additionally, SGM investigator awards were presented to ESIs in September 2018, at an awards ceremony on the NIH campus, and the SGMRO is exploring the possibility of an additional award for established investigators. Such awards assure the community that outstanding contributions to the field are recognized.

Recommendations From the SGMRWG

Work with the National Science Foundation (NSF) to support their efforts in collecting sexual orientation and gender identity in their annual *Graduate Students and Postdoctorates in Science and Engineering* survey to determine representation of SGM populations in biomedical research.

Currently, NSF's graduate student survey is the most comprehensive measure that can reliably collect information on the SGM representation of trainees; surveys from other groups may be able to shed light on issues such as workplace climate and faculty experiences. Gathering these baseline data will help build a foundation of knowledge to support improvements in the training and retention of SGM researchers throughout their careers. Collaborating with other organizations on data collection may be complementary and prove fruitful in gathering additional information on SGM representation within the biomedical research workforce. Lessons learned from NSF should be applied to the NIH for agency-specific data collection efforts.

Conduct an NIH SGM Workshop specifically focused on research related to DSD, sometimes known as intersex.

DSD/intersex research historically has been challenged by its interdisciplinary nature. Little training specific to DSD/intersex exists, and researchers are often siloed within their own disciplines. The SGMRO already holds regional workshops, and a DSD/intersex-focused workshop would provide the opportunity for researchers in disparate fields to convene, identify opportunities for mentorship, and gather information on the NIH grants process. Furthermore, increasing training opportunities related to DSD/intersex research will spur additional relevant applications and lead to expansions in the knowledge and understanding of DSD/intersex.

Collaborate with the Office of Scientific Workforce Diversity (OSWD) to ensure SGM representation in this Office's programs.

A workshop or seminar, co-led by the SGMRO and the OSWD, focused on lessons learned and best practices in understanding and promoting under-represented minorities and women in the biomedical research workforce, may provide an evidence base for moving forward SGM-inclusive initiatives. Although researchers' SGM status may be invisible to colleagues until disclosed—and these individuals probably have experienced discrimination differently than individuals from racial and ethnic minority populations—OSWD has experience ensuring that minority populations are represented in biomedical research training and careers. This experience should be applied to SGM populations so that lessons learned can be used and experience can be adapted to the unique needs of SGM populations. The positive momentum and validation spurred by SGM's designation as a health disparities population should be harnessed. In addition, working toward intersectionality in minority representation will strengthen the community of researchers from all disparity populations. OSWD currently does not include SGM initiatives in its pipeline programs; collaboration with the SGMRO will improve the OSWD's representation, and experienced representatives from this office could speak to SGM career groups and provide advice to strengthen the pipeline for SGM researchers.

GOAL FOUR—Evaluate progress on advancing SGM research.

The SGMRO has conducted reviews and portfolio analyses and prepared reports in accordance with the objectives of Goal Four. Acquiring a Research, Condition, and Disease Categorization (RCDC) code allowed this Office to analyze data from the NIH RePORTER database and provide a more consistent assessment of SGM-related research across the NIH. The measurement-related [Web page](#) on the SGMRO website went live in December 2018. It provides links to SGM methods and measurement-related publications and other data sources, and will provide examples of commonly used sexual orientation and gender identity (SOGI)-related survey questions.

The next Strategic Plan for the SGMRO will cover FY 2021–2025; process development will begin in 2019, followed by data collection in FYs 2019 and 2020, providing the foundation on which to build a plan in FY 2020.

Recommendations From the SGMRWG

Explore the most effective ways to collect and report on the SGM status of participants in clinical research funded by the NIH.

Although the Clinical Center has begun collecting SOGI data, the lack of baseline data on SGM populations remains a challenge. Several ICOs have SGM priority populations within their purview, and coordination with these ICOs to assess SGM inclusion will be necessary to understand the complete picture of SGM populations in NIH research. SGM measures are not currently part of inclusion enrollment reports; encouraging principal investigators to consider inclusion of SGM populations in their studies and tracking such inclusion might help the NIH better understand inclusion-related efforts.

Provide a more exhaustive portfolio analysis, including by SGM population, of NIH-funded SGM research; identify comparison groups for the purposes of conducting analyses.

Further data analysis and more refined data collection on current NIH-funded research with SGM populations will provide a more nuanced assessment of the state of SGM research within the NIH and highlight gaps in research. Much of the research currently conducted with SGM populations is related to HIV/AIDS, although the percentage is decreasing. Other areas of interest should be emphasized. Portfolio data should be disaggregated into HIV/AIDS data, SGM non-DSD/intersex data, and DSD/intersex data for analysis. The SGMRO to date has published available data via the NIH RePORTER database; curated data identifying subpopulations included would be helpful for establishing more specific research opportunities in SGM research.

Include in the next NIH *SGM Research Strategic Plan* goals related to operational activities, as well as scientific opportunities within the field.

The next Strategic Plan should outline specific goals for both operations and scientific opportunities, and these scientific goals should be disaggregated to specifically address the distinct needs of HIV/AIDS research, SGM non-DSD/intersex research, and DSD/intersex-related research. Assembling a scientific plan will require an extensive process that includes consultation with experts in diverse fields, thorough data collection, and public comment periods. Such detailed planning is necessary to address the complex needs of many SGM-related subpopulations within biomedical research. Including scientific goals in the Strategic Plan also will encourage ICOs to further consider and prioritize SGM research within their portfolios.

CONCLUSION

Although much progress has been made since the release of the NIH SGM Research Strategic Plan, several opportunities exist for the expansion of efforts at the NIH that are related to SGM health research. The SGMRWG of the Council of Councils anticipates that implementation of the recommendations included in this report will garner additional progress across the four goal areas of the Strategic Plan.

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