

July 15, 2024

Sexual and Gender Minority Research Office
National Institutes of Health
6555 Rock Spring Drive, Rm. 2SE31J
Bethesda, MD 20817

Re: The National Institutes of Health Request for Information on NIH-Wide Strategic Plan for Sexual and Gender Minority Health Research [NOT-OD-24-122]

Submitted via webform

The Association of American Medical Colleges (AAMC) appreciates the opportunity to provide comments on the National Institutes of Health (NIH) Request for Information on the strategic plan for sexual gender minority (SGM) health research for FY 2026-2030.

The AAMC is a nonprofit association dedicated to improving the health of people everywhere through medical education, health care, medical research, and community collaborations. Its members are all 158 U.S. medical schools accredited by the Liaison Committee on Medical Education; 13 accredited Canadian medical schools; approximately 400 academic health systems and teaching hospitals, including Department of Veterans Affairs medical centers; and more than 70 academic societies. Through these institutions and organizations, the AAMC leads and serves America's medical schools, academic health systems and teaching hospitals, and the millions of individuals across academic medicine, including more than 193,000 full-time faculty members, 96,000 medical students, 153,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences. Following a 2022 merger, the Alliance of Academic Health Centers and the Alliance of Academic Health Centers International broadened participation in the AAMC by U.S. and international academic health centers.

Founded in 2021, the goal of the AAMC Center for Health Justice is for all communities to have an opportunity to thrive, a goal that extends beyond medical care. Achieving health equity means addressing the common roots of health, social, and economic injustices and implementing policies and practices explicitly oriented toward creating genuine opportunities for health. The Center for Health Justice partners with public health and community-based organizations, government and health care entities, the private sector, community leaders, and community members to advocate for health justice through research, analysis, and expertise. For more information, visit www.aamchealthjustice.org.

I. General Comments

The AAMC commends the NIH for its ongoing efforts to engage the scientific research community, clinical practice communities, patient advocates, professional organizations, and other interested parties in the advancement of SGM health research and optimization of the NIH's 2026-2030 Strategic Plan. In 2015, the AAMC submitted comments on the NIH's 2016-2020 Strategic Plan commending the NIH for not only developing a "10-year vision for [...] health equity research, but also a targeted strategy to investigate and improve the health of SGM" communities¹.

¹AAMC Comments, National Institutes of Health FY 2016-2020 Strategic Plan to Advance Research on the Health and Well-Being of Sexual and Gender Minorities (SGM) Request for Comments, 80FR59169
<https://www.aamc.org/media/12506/download?attachment>.

In the 2021-2025 Strategic Plan (referred to herein as the “current plan”), the NIH acknowledges that while progress has been made, “challenges remain in the collection and analysis of sexual orientation and gender identity (SOGI) data. In addition, the developing scientific workforce dedicated to SGM health and research requires further fortification and diversification.”² We fully agree and through the work of the AAMC Center for Health Justice (the Center), the AAMC is committed to building evidence that supports policy changes that will positively impact communities currently and historically underrepresented in health research both as researchers and study participants such as Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual and other sexual and/or gender minority (LGBTQIA+) communities.

A key component of the Strategic Plan is the prioritization of authentic community engagement. Integral to the health justice process of the Center is our ongoing and bidirectional collaboration with the two communities we convene and from whom we solicited input on this response: AAMC CHARGE, a group of over 1,600 health equity champions from across the country including community members,³ and the Center’s Multisector Partner Group, an advisory body comprised of representatives from diverse sectors necessary to achieve health equity.⁴

I. Priorities and Emerging Areas for SGM Health Research at NIH (RFI Topic 1 and 2)

Community Engagement

In the AAMC’s letter to the NIH on the 2016-2020 Strategic Plan, we underscore the need for the NIH to seek input from *diverse* SGM communities to ensure that *all* interested parties have the opportunity to shape the vision for SGM health research.

The current plan has four main goals with Goal 2 focused on “fostering partnerships and collaborations with a strategic array of internal and external stakeholders,” using only these broader terms without explicitly mentioning the engagement of LGBTQIA+ community. **We recommend that NIH include the term “LGBTQIA+ populations” or “SGM populations” to ensure members of these communities and the organizations who are not current NIH partners are specifically included in developing the NIH’s SGM research priorities and agenda.**

We also suggest adding a new objective to Goal 2 that supports the development of mechanisms for meaningful engagement with diverse SGM communities, including those that are racially and ethnically diverse. It would benefit the NIH to refer to current government efforts focused on developing an infrastructure that supports long term and authentic community relationships:

- White House Office of Management and Budget (OMB)— The OMB is in the formative stages of developing a government-wide framework for public participation and community engagement with a focus on engaging diverse populations (*see AAMC Center for Health Justice Comments to OMB RFI on Community Engagement*⁵).

² NIH Strategic Plan Fiscal Years 2021-2025, https://dpcpsi.nih.gov/sites/default/files/SGMStrategicPlan_2021_2025.pdf (accessed July 4, 2024).

³ Learn more about AAMC Center for Health Justice CHARGE: <https://www.aamchealthjustice.org/get-involved/aamc-charge>.

⁴ Learn more about AAMC Center for Health Justice Multisector Partner Group: <https://www.aamchealthjustice.org/multisector-partner-group>.

⁵AAMC Comments to White House Office of Management and Budget, Re: Methods and Leading Practices for Advancing Public Participation and Community Engagement With the Federal Government, Document Number: 2024-05882 (88 FR 19885) (May 17, 2024), <https://www.aamc.org/media/76946/download?attachment>.

- Environmental Protection Agency (EPA)— The EPA is also taking steps to update its 2003 *Meaningful Involvement Policy*, which provides detailed recommendations on how to engage communities and build trust with those communities.⁶ The EPA describes “meaningful engagement” in the 2023 draft policy as the “[...]commitment to a public participation process that seeks and facilitates public input on EPA actions by providing timely and culturally appropriate information, access for people with disabilities, and language access for persons with limited English proficiency, considering issue of access raised by location, transportation, and other factors affecting participation, and by making available technical assistance to build community-based capacity for participating.”⁷
- Principles of Community Engagement publication—The fourth edition of *Principles of Community Engagement*, developed by the Clinical and Translational Science Awards Consortium is forthcoming and will likely be responsive to the changes in the social environment, including the growth of community engaged research.⁸

The activities described above are in furtherance of Executive Order (EO) 14091, *Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, which requires federal agencies to create equity action plans. Pursuant to EO 14091 and related EO, historic steps to address LGBTQIA+ inequities have been taken such as the “the first-ever National Strategy on Gender Equity and Equality to ensure that all people regardless of gender, have the opportunity to realize their full potential.”⁹ The AAMC expressed strong support for these efforts in our response to the OMB’s RFI on ways to advance equity for underserved communities, recommending the government focus on developing authentic ways to partner with those communities.¹⁰

Authentic partnership between NIH and LGBTQIA+ communities could also be advanced through incorporation of the AAMC Center for Health Justice’s Principles of Trustworthiness, which were co-created with community members from across the U.S. and provide guidance on how to build authentic, long-term community partnerships.¹¹ Incorporating the Center’s Principles of Trustworthiness and corresponding toolkit into the implementation strategy for this Strategic Plan could help to better facilitate relationships with individuals and communities that can contribute diverse perspectives on sex, gender, and identity.

Workforce Development

⁶ EPA Meaningful Involvement Policy, <https://www.epa.gov/environmentaljustice/epas-meaningful-involvement-policy> (Accessed July 4, 2024).

⁷ *Id.*

⁸ Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, <https://www.atsdr.cdc.gov/communityengagement/index.html> (accessed July 4, 2024).

⁹ Executive Order on Further Advancing Racial Equity and Support for Underserved Communities Through The Federal Government (February 16, 2023), <https://www.whitehouse.gov/briefing-room/presidential-actions/2023/02/16/executive-order-on-further-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/> (accessed July 4, 2024).

¹⁰ AAMC Center for Health Justice Comments, RE: OMB Request for Information: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government, OMB 2021-0005.

¹¹ AAMC Center for Health Justice Principles of Trustworthiness, <https://www.aamchealthjustice.org/our-work/trustworthiness/trustworthiness-toolkit>.

We are encouraged by the NIH’s commitment to identifying training gaps and opportunities that build a diverse and skilled workforce (Goal 3). We recommend to NIH the AAMC’s related comments on the NIH’s broader efforts to increase workforce diversity to the *Draft Chief Office for Scientific Workforce Diversity Strategic Plan for FY 2022-2026* and *Draft NIH Strategic Plan for Diversity*.¹² In addition, we make the following considerations:

- **Identify Barriers to Workforce Participation in Goal 3, Objective 4**— We recommend that NIH identify barriers that prevent diverse SGM populations and subpopulations from participating in the NIH workforce in Goal 3, Objective 4 (“Encourage the recruitment and retention of SGM researchers in the health research workforce”), which can lead to further marginalization and negative impacts on the progress of research and local SGM research partnerships. As has been documented, “[d]iscriminatory environments can stigmatize sexual minorities and reduce their self-esteem and confidence, which may lead to adverse health and risk-taking behaviors. Previous research has noted that sexual minorities living in states without legal protections (e.g., same-sex marriage) were more likely to report symptoms of depression, anxiety, and alcohol use disorder.”¹³ As part of Goal 3, we also recommend the collection and analysis of NIH workforce data (including state level data) to identify barriers to workforce participation such as potential discrimination and unequal treatment.
- **Include the Word “Diverse” in Goal 3 Objective 4**—We recommend adding the phrase “diverse SGM researchers” to promote the development and implementation of strategies that attract and retain racially, ethnically, culturally, and economically diverse individuals, including individuals with diverse abilities, skills, and lived experiences.
- **Solicit Input from SGM Organizations and Advocates**—The NIH should solicit additional feedback from local and national organizations and networks dedicated to increasing visibility and access for LGBTQIA+ researchers (e.g., Out to Innovate – “a professional society and global community of LGBTQIA+ students and professionals” in STEM and Out in Science, Technology, Engineering, and Mathematics¹⁴). These collaborations could help the NIH develop strategies to address persistent challenges faced by SGM researchers, create impactful mentorship and career development opportunities, develop culturally appropriate trainings for NIH leadership on LGBTQ+ issues, and identify ways to promote a supportive and inclusive environment.

Standardized Data Collection for SGM Populations

In the AAMC’s letter to the NIH on the 2016-2020 Strategic Plan we encouraged the NIH to conduct an analysis of its health equity research portfolio “to identify and work to close any gaps in ... populations targeted by NIH-funded health disparities research.” We reiterate that recommendation and urge NIH to further identify segments of the SGM population for whom research should be prioritized. We support the NIH’s goals to make SOGI data collection more rigorous and widespread, and also emphasize the importance of the accurate measurement of SOGI. This concern has also been highlighted by the National Academies, which noted that “most [data collection] efforts have long treated sex and gender as binary,

¹² AAMC Comments to NIH, Draft NIH Chief Officer for Scientific Workforce Diversity Strategic Plan for FYs 2022-2026 (NOT-OD-22-054), <https://www.aamc.org/media/58846/download?attachment>; See also, AAMC Comments Inviting Comments and Suggestions on a Framework for the NIH-Wide Strategic Plan for Diversity, Equity, Inclusion, and Accessibility, <https://www.aamc.org/media/60231/download?attachment>.

¹³ Gonzales G, Ehrenfeld JM. The Association between State Policy Environments and Self-Rated Health Disparities for Sexual Minorities in the United States. *Int J Environ Res Public Health*. 2018 Jun 1;15(6):1136. doi: 10.3390/ijerph15061136. PMID: 29857580; PMCID: PMC6024973.

¹⁴ Out to Innovate, <https://oti.memberclicks.net/>; oSTEM <https://ostem.org/> (accessed July 10, 2024),

mutually determined (usually at birth), and interchangeable constructs that can each serve as a proxy for the other.” The report also notes that “[t]his simple binary, however, masks a more complicated reality in which a constellation of sex traits may not all correspond to the same sex ... These measurement issues are not purely academic: they can have severe consequences for sexual and gender minorities in health care and other areas in which measures of sex/gender and sexual orientation are often used for determining appropriate and necessary care.”¹⁵ Below, we offer two key recommendations that we believe will help NIH meet the objectives in Goal 4:

- **Standardize Sexual Orientation and Gender Identity (SOGI) Data Collection** — In March 2024, the OMB released revisions to its standards for collecting and presenting federal data on race and ethnicity (“SPD 15”).¹⁶ These updates implement government-wide principles and policies on how data are collected and shared across the federal government. The OMB made several important changes to SPD 15 from the inclusion of a new race and ethnicity category (i.e., Middle Eastern North African), asking race and ethnicity in a combined question, and the collection of more detailed data as a default. While SPD 15 provides for the collection of detailed data, it does not require the collection of SOGI data.

As detailed in the HHS Fact Sheet on *Advancing Health Equity Across the Department of Health and Human Services*: “[s]tarting in 2026, many certified health information technology products will need to support new data elements that promote health equity including SOGI data and Social Determinant of Health assessment data [...]”¹⁷ In addition to the *HHS-wide SOGI Data Action Plan*, HHS highlights other federal efforts to incorporate SOGI data collection in agency programs and initiatives such as the Centers for Medicare and Medicaid Services (CMS) who recently added new optional questions for the collection of SOGI data as part of state programs.¹⁸

Given the interest across agencies to develop measures for collecting data on sex and gender, we recommend the NIH convene interested agencies and community partners (e.g., SGM organizations, research institutions, public and private organizations) in a discussion on the standardization of validated SOGI questions, including the collection of data related to the intersection of SGM status with other facets of identity (e.g., race, disability, economic status), and the benefits of SGM data in the broader efforts to improve clinical trial diversity (see Food and Drug Administration *Draft Guidance on Diversity Action Plans Required for Certain Clinical Studies*¹⁹). We also recommend sharing the lessons learned and recommendations discussed during these convenings in the form of a publicly available report. Additional issues and topics the NIH should consider as part of this effort:

- **Agency Assessment**—Assess other federal agencies collecting SOGI data in coordination with the OMB’s *Interagency Committee on Race and Ethnicity Statistical Standards*. This should include but not be limited to HHS, Department of Justice, CMS, Office of the National Coordinator for Health

¹⁵ National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.

¹⁶ OMB Publishes Revisions to Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, <https://www.whitehouse.gov/omb/briefing-room/2024/03/28/omb-publishes-revisions-to-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity/> (accessed July 4, 2024).

¹⁷ Fact Sheet: Advancing Health Equity Across HHS, <https://www.hhs.gov/equity/fact-sheet-advancing-health-equity-across-hhs/index.html> (accessed July 4, 2024).

¹⁸ Tran NM, Nguyen KH. LGBTQI+ Data Collection in Medicaid to Advance Health Equity. *JAMA*. Published online June 26, 2024. doi:10.1001/jama.2024.7829

¹⁹ FDA News Release: FDA Guidance Provides New Details on Diversity Action Plans Required for Certain Clinical Studies (June 26, 2024), <https://www.fda.gov/news-events/press-announcements/fda-guidance-provides-new-details-diversity-action-plans-required-certain-clinical-studies> (accessed July 4, 2024).

Information Technology, Department of Agriculture, Substance Abuse and Mental Health Services Administration, Indian Health Service, Agency for Healthcare Research and Quality, and the Administration for Children and Families.

- **Terminology and Definitions** — Conduct an evidenced based review of current terminology and definitions (e.g., sex, gender, transgender, sexual orientation) to ensure terms are not offensive, appropriate, and accurate to sexual and gender minorities.
- **Community Advisory Board** — Establish a community advisory board that consists of SGM individuals and advocates to assist agencies with the review of issues related to the collection of SGM data, including the implementation of the OMB’s *Agency Action Plans on Race and Ethnicity* as required by SPD 15.
- **Ongoing Evaluation**— While the OMB recommends the evaluation of SPD 15 on a 10-year cycle, we recommend a review of the NIH’s data collection activities every three years as we recommended in our comments to OMB.

Measure the Impact of Anti LGBTQIA+ Policy

Research has demonstrated that an overwhelming number of LGBTQIA+ individuals experience discrimination, victimization, and negative psychological and behavioral health impacts due to anti-LGBTQIA+ laws and policies.²⁰ The AAMC has considered the impact of anti-LGBTQIA+ policies in the AAMC Center for Health Justice Brief, *To Protect Evidence-Based Medicine and Promote Health Justice, Protect Gender-Affirming Medical Care*²¹ estimating that over 132,000 transgender youth alone face threats to their medical care and mental health as the result of the rise of proposed and enacted anti-LGBTQIA+ policies.

Pursuant to the executive orders on advancing racial equity for underserved communities and *Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals*,²² NIH should promote an evidence-based approach to understanding the public attitudes toward sexual orientation (e.g., measuring heterosexism, cissexism, and intersecting forms of discrimination)²³ and fund research to understand and quantify the health impacts of anti-LGBTQIA+ policies, not just for members of the SGM community but for U.S. society as a whole.

Building Partnerships

The AAMC Center for Health Justice has developed extensive relationships across various sectors, including trusted partnerships with individuals, organizations and community leaders who are deeply committed to advancing health equity and social justice in partnership with the federal government. Community wisdom should guide our collective initiative toward creating lasting solutions that address the diverse needs of all individuals and communities.

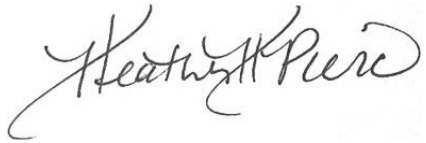
²⁰ New Poll Emphasizes Negative Impacts of Anti-LGBTQ Policies on LGBTQ Youth <https://www.thetrevorproject.org/blog/new-poll-emphasizes-negative-impacts-of-anti-lgbtq-policies-on-lgbtq-youth/> (accessed July 10, 2024).

²¹ To Protect Evidence-Based Medicine and Promote Health Justice, Protect Gender-Affirming Medical Care <https://www.aamchealthjustice.org/news/policy/gamc-trans-youth>.

²² <https://www.whitehouse.gov/briefing-room/presidential-actions/2022/06/15/executive-order-on-advancing-equality-for-lesbian-gay-bisexual-transgender-queer-and-intersex-individuals/>

²³ James, D. Initial Development and Validation of the Brief Internalized Heterosexist Racism Scale for Gay and Bisexual Black Men: A Measure of Internalized Heterosexist Racism. *Arch Sex Behav* **53**, 1307–1325 (2024). <https://doi.org/10.1007/s10508-023-02805-1>

We value the opportunity to contribute to this initiative and are grateful that we are able to amplify the expertise of the Center's community. For questions about these comments or if there is an interest in learning more about how the NIH might incorporate the Center's Principles of Trustworthiness into the next iteration of the NIH-wide Strategic Plan, please contact us or our colleague Daria Grayer, MA, JD, AAMC Director of Policy and Regulations and Director of Policy for the Center for Health Justice (dgrayer@aamc.org).



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