

## Sexual and Gender Minority Health Research at the National Institutes of Health

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### Abstract

Sexual and gender minority (SGM) populations experience many diseases and conditions at higher prevalence rates than their non-SGM counterparts. In 2009, the National Institutes of Health (NIH) commissioned an Institute of Medicine (IOM) report to better understand the health of SGM populations. Following the release of the report, NIH, including the National Cancer Institute (NCI), initiated new activities, and continued and expanded its existing efforts to advance the health of SGM individuals. Such efforts include various forms of outreach to solicit feedback, support of extramural researchers, analysis of the research portfolio to identify areas of opportunity, and the development of the NIH Strategic Plan for SGM Health Research.

**Key words:** biomedical research, National Institutes of Health (NIH), sexual and gender minority, strategic plan.

### Introduction

THE MISSION OF the National Institutes of Health (NIH) focuses on improving the health of the nation, by seeking both knowledge of the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.<sup>1</sup> Through its Institutes and Centers (IC), as well as its Offices, the agency fulfills that mission by supporting and conducting research on its campuses (intramural research) and funding research at universities and research institutions (extramural research).<sup>1</sup>

In 2009, NIH took an important step towards realizing that mission with regard to sexual and gender minority (SGM) populations by commissioning the National Academies of Sciences (NAS) Institute of Medicine (IOM) to develop a report on lesbian, gay, bisexual, and transgender (LGBT) health. “Sexual and Gender Minority,” is an umbrella term that encompasses lesbian, gay, bisexual, and transgender (LGBT) people, as well as those whose sexual orientation and/or gender identity varies, those who may not self-identify as LGBT (e.g., Queer, Questioning, Two-Spirit, Asexual, men who have sex with men [MSM], Gender-variant), or those who have a specific medical condition affecting reproductive development (e.g., individuals with differences or disorders of sex development [DSD], who

sometimes identify as intersex). A major impetus for the IOM study was the lack of an in-depth, state-of-the-science study on SGM populations and their possible increased risks for certain diseases and conditions. SGM populations are estimated to deal with depression and anxiety at rates up to 1.5 times higher than non-SGM individuals.<sup>2</sup>

Cancer also affects SGM populations at disproportionate rates, with 14% of lesbian women and 17.6% of bisexual women reporting cancer diagnoses, as compared to only 11.9% of heterosexual women.<sup>3</sup> Men who have sex with men have a higher prevalence of anal cancer than men in the general population<sup>4</sup> and bisexual women have the highest rates of breast cancer at 8.4%.<sup>3</sup> Lesbians and bisexual women have a higher prevalence of cigarette smoking than heterosexual women<sup>5</sup> and are also less likely to receive a Papanicolaou (PAP) test.<sup>6</sup>

The IOM study, released in 2011, recommended a number of steps that would facilitate both NIH’s and the Department of Health and Human Services’ (HHS) efforts to better address the health of SGM individuals.<sup>7</sup> These included the development of a research agenda, enhanced data collection on sexual orientation and gender identity across federally funded surveys and in electronic health records, and NIH support of methodological research and standardized measures for sexual orientation and gender identity measures.<sup>7</sup>

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Following the release of the report, NIH established the first-ever trans-NIH research coordinating committee focused on health research specific to SGM populations (currently the NIH Sexual and Gender Minority Research Coordinating Committee [RCC]).<sup>8</sup> This committee was the conduit through which the agency began its work both to absorb the information the IOM report provided, and to determine how best the agency could consider and address the recommendations. In 2013, NIH released a report, which included a portfolio analysis of FY2010 NIH-funded LGBT health research.<sup>9</sup> The results of the NIH report and portfolio analysis aligned with many of the findings in the IOM study, including opportunities for research on health inequities in LGBT populations, health risks and protective factors for LGBT populations across their life course, transgender-specific health needs, and the needs of children diagnosed with DSD, as well as their families.<sup>9</sup>

### Development of the NIH SGM Health Research Strategic Plan

The efforts of the IOM and of NIH's own internal deliberations provided a substantive basis and the impetus for developing an NIH SGM Health Research Strategic Plan. To inform the strategic plan, NIH embarked on a series of activities designed to further engage with and obtain input from stakeholders, including researchers in SGM health, advocates, and the general public. The activities ranged from listening sessions to public requests for information to portfolio analyses.

The two top-ranking officials at NIH presided over its first-ever listening session on lesbian, gay, bisexual, transgender, and intersex (LGBTI) Health Research on June 27, 2013.<sup>10</sup> Drs. Francis Collins and Lawrence Tabak (the NIH Director and Principal Deputy Director, respectively) met with SGM health researchers and advocates, in person and via webcast, to get a general sense of what these communities identified as important research needs for the health of sexual and gender minorities.<sup>10</sup> That first session was a kick-off, of sorts, to a succession of listening sessions that focused on more specific areas within the SGM health umbrella, including transgender health and intersections of race and sexual and/or gender minority status. To ensure that the agency reached as many stakeholders as possible, NIH also released a public Request for Information (RFI) on the priority areas in LGBTI health, using the recommendations from the IOM report as the framework for the RFI.<sup>11</sup>

These efforts provided NIH with both broad and detail-driven input from SGM stakeholders. For example, research in the past has been limited only to certain demographics within the SGM community, although the population experiences a wide range of health issues specific to their SGM status (e.g., DSD). Input from the community has helped the NIH and researchers better understand those differences. Respondents emphasized the need for additional SGM-focused tobacco and cancer research, and research on DSD conditions, Native Americans who identified as Two-Spirit, and transgender health care.<sup>11</sup> They also clearly expressed desire to see movement in the direction of the IOM report recommendations.

In addition to engaging with external stakeholders, NIH worked within its own ranks to seek input from staff across the agency—Institute and Center directors, program officers,

those involved in scientific review, and many others. The SGM RCC also conducted a second portfolio analysis of NIH-funded SGM health research, this time on the FY2012 portfolio. The ensuing report was released earlier in 2015.<sup>12</sup> Throughout all of these endeavors, NIH staff shared information with and brought back feedback from the extramural community on the agency's efforts, when presenting at scientific conferences.

While much of the information gleaned through these efforts already was covered in the IOM report, this process proved important on a number of fronts. It ensured that NIH gained the widest possible range of input from stakeholders. It also strengthened and established connections between NIH and the SGM stakeholder community. These connections provided essential input for the strategic plan, and also gave NIH insight into how best to engage in and support consistent and candid conversations with researchers and advocates.

This insight also came from internal NIH communications and idea sharing around SGM health research needs, and emphasized the need for an NIH coordinated effort around better understanding the health needs of SGM populations.

### Enhancing Coordination of SGM Health Research Efforts

This kind of coordination continues through the launch of multiple initiatives, programs, and events focused on SGM research. The establishment of a web presence for NIH SGM Health Research also allows for interactive communication between the SGM RCC and SGM health research stakeholders. In August 2015, NIH released an announcement requesting applications for a program providing research supplements to existing funded NIH research to include and expand research questions relevant to SGM health.<sup>13</sup> This initiative will facilitate turning an SGM-relevant "lens" on research topics for which there is already significant support, including and beyond the arena of HIV/AIDS, thereby, both acknowledging the range of health issues facing SGM populations and enhancing the knowledge base around health inequities in the SGM communities.

NIH also released a series of Funding Opportunity Announcements (FOA) for new projects focused on SGM populations to further improve what is understood in this area.<sup>14</sup> The agency continues to engage with the extramural community through specific IC-driven efforts, including scientific activities on DSD, and workshops focused on preventing HIV in diverse populations of men who have sex with men (held by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development [NICHD] and the National Institute on Minority Health and Health Disparities [NIMHD], respectively).<sup>15,16</sup>

The National Cancer Institute (NCI), the largest of the Institutes/Centers at NIH, is committed to supporting SGM-focused research and to exploring the methodological challenges in conducting research in this population. NCI has demonstrated this commitment by establishing a trans-NCI SGM Committee to improve communication and collaboration in SGM research in both the intramural and extramural communities at NCI.

NCI participates in various NIH-wide Program Announcements and funds its own research in this area. The

ANCHOR—Anal Cancer/HSIL Outcomes Research—trial conducted through the NCI-supported AIDS Malignancy Consortium, is a multi-center phase III clinical trial that aims to determine if screening for and treating HSIL in HIV-positive individuals can prevent anal cancer from developing; engagement from the HIV community will be one key to its success.<sup>17</sup> In 2015, NCI co-sponsored a workshop, along with NICHD and the National Institute of Allergy and Infectious Diseases (NIAID) that brought together leaders in the field of transgender health. Recommendations from that workshop will provide NCI leadership guidance on potential areas of exploration in cancer and the transgender community.

NCI also brought together a multi-disciplinary team of experts in September 2015 to explore opportunities for understudied populations, including the SGM community. The NCI-sponsored workshop, *Understudied Populations in Cancer Epidemiologic Research: Implications on Future Needs*, looked to expand upon on-going efforts, identify resources, and set priorities in cancer epidemiology research among understudied populations.

These activities, along with others, are initial steps in NCI's efforts to gain a better understanding of the cancer burden within the SGM community. This understanding will provide a platform for additional focus on the health and research needs of this long-neglected community.

In October 2015, NIH released for public comment its inaugural Strategic Plan for SGM Health Research. This Strategic Plan, which covers the years 2016–2020, will provide a framework for progress in basic, clinical, and behavioral and social sciences research to improve the health of SGM populations. The plan will center on expanding the knowledge base of SGM health and well-being through NIH research, removing barriers to planning, conducting, and reporting NIH-supported SGM research, and strengthening the community of SGM researchers. The research that results from this plan will lay the foundation for improved health and well-being among a group of diverse SGM individuals whose health needs have not traditionally received strong attention from the research community.

## Conclusion

This is truly an exciting time for SGM health research at NIH, and it is the culmination of a lot of time and effort from a lot of people, both within NIH, and in the extramural community and the general public. Initiatives such as this special cancer issue of *LGBT Health* provide a space to share and learn more about the gaps and opportunities present in SGM health. As mentioned previously, some cancer rates in SGM populations surpass those of their heterosexual counterparts, and there is no denying the devastating impact of this disease on those communities.

NIH is committed to maximizing its efforts on SGM health research to generate new data and understanding around SGM health. This understanding will include not only health inequities, but also persistence and resiliency in those who identify as sexual and gender minorities. NIH strives to improve health for all Americans, and we look forward to making certain that applies to all SGM communities.

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## Author Disclosure Statement

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