National Institutes of Health FY 2012 Sexual and Gender Minority Health Research Portfolio Analysis Report

April 2015

Submitted by the NIH SGM Research Coordinating Committee Chairs: Nathan Stinson, Jr., Ph.D., M.D., M.P.H. and Elizabeth Wehr, J.D.

Portfolio Analysis

Table of Contents

EXECUTIVE SUMMARY **1**

Opportunities and Gaps in Research and Areas for Future Study 2

INTRODUCTION **4**

METHODOLOGY **5**

RESULTS **6**

Administering NIH Institute or Center 6

Priority Research Areas Identified in the IOM Report 6

Priority Health Conditions 7

Population Focus 9

NIH Grant, Cooperative Agreement, and Contract Mechanisms 12

Type of Funding Opportunity Announcement (FOA) 14

Opportunities and Gaps in Research and Areas for Future Study 16

APPENDICES **17**

Appendix A: Methods for Conducting the Portfolio Analysis 17

Appendix B: NIH Institutes, Centers, and Offices Represented on the NIH SGM RCC 19

Appendix C: Glossary of NIH Activity Codes 20

Appendix D: NIH SGM Projects by Activity Code 21

Appendix E: NIH SGM Research Coordinating Committee 22

EXECUTIVE SUMMARY

This report of the National Institutes of Health (NIH) Sexual and Gender Minority (SGM) Research Coordinating Committee (RCC) is an analysis of the ongoing NIH research portfolio in SGM health. In response to the March 31, 2011 report of the Institute of Medicine (IOM) entitled, *The Health of Lesbian, Gay, Bisexual and Transgender People*, the RCC was charged with "developing and coordinating potential research and training opportunities to be undertaken at the NIH as a result of recommendations from the IOM report." SGM is an umbrella term that encompasses lesbian, gay, bisexual and transgender (LGBT) populations as well as those whose sexual orientation, gender identity/expressions or reproductive development varies from traditional, societal, cultural, or physiological norms.

The RCC analyzed the FY 2010 NIH portfolio of research activities in the area of SGM health in order to establish a baseline in the science funded by the NIH. It also represented a starting point for the implementation of the IOM recommendations. The RCC opted for a conservative approach, including only those projects for which investigators explicitly identified one or more SGM populations as target populations for the research. The analysis omitted projects of secondary applicability, i.e., projects that did not specifically identify SGM populations as participants, but may have yielded data on health or health risks of SGM individuals, such as research on runaway and homeless youth. The portfolio analysis did not examine budgets, so no financial data are associated with this analysis. The same general procedures used for the FY 2010 portfolio analysis were used to analyze the FY 2012 portfolio with a few notable changes. Loan Repayment Program (LRP) awards and projects addressing intersex/differences or disorders of sex development (I/DSD) conditions were included in the analysis. The search terms men who have sex with men (MSM) and men who have sex with men and women (MSMW) were added to the existing algorithm for identification of relevant research projects.

During FY 2012, a total of 13 NIH Institutes/Centers (ICs) supported 279 SGM projects. NIAID, NICHD, NIDA, NIMH, and NIMHD administered the majority of projects, together accounting for 249 or nearly 90% of all SGM projects. Projects in the SGM portfolio are represented by a variety of different activity codes, including research projects grants, center grants, infrastructure grants, training grants, career development awards, loan repayment awards, and intramural research projects. R01 research project grants and R21 exploratory/developmental grants comprise the largest proportion of projects (39.4% and 10.4%, respectively).

Projects were categorized according to whether they were submitted to a Program Announcement (PA), PA with set-aside funding (PAS), PA with special review (PAR), or Request for Applications (RFA). Although LRP awards are technically contracts, LRP awards were placed in the RFA category since they are peer-reviewed by the ICs, similar to applications submitted to an RFA. Of the 270 projects with an associated funding opportunity announcement (FOA), nearly 60% were submitted to a PA and just over one-quarter (26.7%) were submitted to an RFA. Intramural projects and a small number of extramural grants, which are not associated with a particular FOA, composed the remaining 9 projects. Also, the majority (68.5%) of projects were submitted to FOAs that were not SGM-specific. About one-fourth were submitted to *SGM-Relevant* FOAs. Only 5.6% of projects were submitted to *SGM-Focused* FOAs.

Among the eight research priority areas in SGM health identified in the IOM Report, *Intervention Research* and research addressing *Social Influences* were the IOM priority areas most frequently addressed in the NIH research projects. Projects concentrated on *HIV/AIDS* are linked topically with the

Social Science category, and virtually all projects related to Prevention also focused on HIV/AIDS. Another large group of projects includes *Chronic Disease*, with smaller concentrations in the areas of *Infectious Disease*, *Drug Abuse/Substance Abuse*, *Translational Research*, *Epidemiology*, and *Sexually Transmitted Diseases*. Other research areas are less frequently represented in the portfolio.

The identification of the target SGM populations included in each research project revealed that MSM were by far the most commonly represented population (68.8%). Women, including lesbians, bisexual women, and women who have sex with women (WSW), were not frequently represented in the portfolio nor were transgender individuals and individuals with I/DSD conditions. The RCC and the IOM identified a need for SGM research across the lifespan, particularly with respect to youth and the elderly. Results indicate that 40% of projects had a youth focus or a combined youth/adult focus, and are largely characterized by HIV prevention studies in adolescent and young adult MSM. In contrast, only 3% of studies had an elderly focus.

Summary of FY 2012 NIH SGM Research Portfolio Analysis:

- During FY 2012, a total of 13 NIH Institutes/Centers supported 279 SGM projects.
- NIAID, NICHD, NIDA, NIMH, and NIMHD administered the majority of projects, together accounting for 249 (or nearly 90%) of all SGM projects.
- R01 research project grants and R21 exploratory/developmental grants comprise the largest proportion of projects (39.4% and 10.4%, respectively).
- Also, the majority (68.5%) of projects were submitted to FOAs that were not SGM-specific.
- Virtually all projects related to Prevention focused on HIV/AIDS.
- Men who have sex with men (MSM) were by far the most commonly represented SGM population in NIH-funded studies (68.8%).

Opportunities and Gaps in Research and Areas for Future Study

The FY 2010 SGM portfolio analysis identified the portfolio (n=232) as largely focused on HIV/AIDS with MSM. Mental health and substance abuse issues, again largely with MSM, were also well represented in the portfolio. Research on other SGM population groups and other health conditions was less frequently represented, and in general, the portfolio did not address many of the research opportunities and gaps identified in the IOM report. The FY 2012 SGM (n=279) portfolio appears to be similar to the FY 2010 portfolio in size (after adjusting for the addition of LRP awards, MSM, MSMW, and I/DSD search terms) as well as primarily focused on HIV/AIDS research with MSM. When examined separately, I/DSD projects appear to demonstrate a different pattern, with the bulk of research in this area being pre-clinical or clinical research to understand the etiology and manifestations of these conditions. Thus, across SGM populations, critical gaps in and opportunities for better understanding the health needs and lived experience of SGM individuals remain. Further research is still needed in the broad areas identified in the IOM report, the FY 2010 SGM portfolio analysis report, and this analysis.

[The FY2012 NIH SGM portfolio does not include applications submitted to the 2012 issued *Research on the Health of LGBTI Populations* (R01, R03, R21 activities) FOAs because applications responsive to the FOA were funded in FY 2013.]

INTRODUCTION

The Institute of Medicine the (IOM) report, *The Health of Lesbian, Gay, Bisexual and Transgender People* issued March 21, 2011, highlighted the health challenges faced by sexual and gender minority (SGM) populations. SGM is an umbrella term that encompasses lesbian, gay, bisexual and transgender (LGBT) populations as well as those whose sexual orientation, gender identities/expressions or reproductive development varies from traditional, societal, cultural or physiological norms. Often, members of this population identify as lesbian, gay, bisexual, transgender, or intersex (LGBTI). They may also identify as queer, questioning, Two Spirit, asexual, gender variant, or some other terminology, including diagnostic categories referred to sometimes as differences or disorders of sex development (DSD).

Recent data from the 2013 National Health Interview Survey (NHIS) found that 1.6% of U.S. adults identified as gay or lesbian, 0.7% identified as bisexual, and 1.1% identified as "something else," stated "I don't know the answer," or refused to answer. The survey also found several significant differences among those U.S. adults who identified as straight, gay or lesbian, or bisexual in such factors as health-related behaviors, health status, and health access. As the NHIS data suggest, SGMs have distinct health issues that call for research in areas, including but not limited to: aging, cancer risk, cardiovascular disease, depression, endocrine conditions, exposure to violence (community, domestic), long-term hormone use, risk for infectious diseases, effects and impact of stigma (minority stress), obesity, suicide, and tobacco and alcohol/drug use. Research is also needed on resilience and other protective factors that mitigate SGM health risks.

The specific IOM recommendations for addressing SGM health highlighted the need to deliberately and comprehensively:

- Implement a research agenda
- Collect sexual orientation and gender identity data using federally funded surveys and in electronic health records
- Develop standardized gender identity measures
- Support methodological research related to SGM health
- Create a comprehensive research training approach to strengthen SGM health
- Encourage grant applicants explicitly to address the inclusion or exclusion of sexual and gender minorities in other samples

In response to the IOM Report, the NIH established the LGBT Research Coordinating Committee (RCC), subsequently reconstituted as a permanent staff committee referred to as the Sexual and Gender Minority (SGM) RCC. The RCC provides an important forum at NIH for discussing the diverse health issues for these communities and serves as a catalyst for developing additional research and research training initiatives for advancing research in these areas. Specific NIH SGM RCC responsibilities include:

- Facilitating and coordinating collaborations and other activities related to SGM health research across the NIH Institutes, Centers, and Offices (ICOs) as well as with other Federal agencies
- Developing potential research and research training activities for NIH and ICO leadership to consider as a result of recommendations from the IOM report on LGBT health
- Developing and recommending strategies to track and monitor NIH research initiatives and progress in this area
- Coordinating reporting on SGM research activities to the Department of Health and Human Services (DHHS)

METHODOLOGY

While NIH has an ongoing research effort related to SGM health, ongoing monitoring of the portfolio is needed to help us better understand health risks, conditions, and protective factors across the lifespan associated with variation in sexual orientation and gender identity. The RCC previously analyzed the FY 2010 NIH portfolio of research activities in the area of SGM health as a baseline in understanding the science funded by the NIH and a starting point for the implementation of the IOM recommendations.

The RCC portfolio analysis provides a snapshot of a specific fiscal year as a basis for considering the IOM recommendations. It is important to note that this analysis concentrated on the scientific topics that constitute NIH's research foci, and not the amount of NIH's investments. Given the goal of identifying scientific opportunities and research gaps, no financial data are associated with this analysis. The process for how the RCC conducted the portfolio analysis, together with any limitations, is described in Appendix A. The RCC opted for a conservative approach, including only those projects for which investigators explicitly identified one or more SGM populations as target populations for the research. The analysis omitted projects that may also yield data on health or health risks of sexual or gender minorities, such as research on runaway and homeless youth, but that do not specifically identify SGM populations as participants.

The IOM report identified "intersexuality" as a "type of 'otherness' that is stigmatized and overlaps in some areas with LGBT identities and health issues." This language refers to approximately 40 congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical. These conditions are typically recognized at or shortly after birth, although some are not recognized until puberty. While acknowledging that very little research exists on the health and health risks of individuals with these conditions, the IOM report indicated that the conditions constitute "a separate research topic with critical issues, most not related to LGBT issues, and hence beyond the scope of the IOM LGBT report." The NIH agrees with the IOM that these conditions, now often referred to as "differences" or "disorders of sex development (DSD)" or by specific diagnoses (e.g., congenital adrenal hyperplasia) raise unique research issues. The NIH also recognizes that affected individuals vary in their preferences for terminology and association with LGBT communities. In order to stimulate research in the health of all understudied sexual and gender minority populations, NIH has elected to include I/DSD conditions in its SGM RCC activities, including this analysis, to promote such research.

The same general procedures used for the FY 2010 portfolio analysis, outlined in Appendix A, were used to analyze the FY 2012 portfolio, with the following adjustments:

- Loan Repayment Program (LRP) awards are now included, and classified with other NIH training activities, such as those in the 'T' or 'F' series. LRP awards enable recipients to defray a substantial part of their educational expenses in exchange for conducting research activities. These awards do not specifically target or directly support SGM research; however, LRP awards support individuals to enable them to conduct SGM research.
- The search terms men who have sex with men (MSM) and men who have sex with men and women (MSMW) were added to the existing algorithm for identification of relevant research projects. Also added are projects on I/DSD conditions, as mentioned above.
- Text mapping is used in addition to descriptive statistics about grants to provide an additional graphical depiction of the SGM portfolio.

RESULTS

The NIH support for existing research programs or initiatives in SGM health for FY 2012 consisted of a total of 279 projects, including 23 (8.2%) on populations with I/DSD conditions.

Administering NIH Institute or Center (IC)

As shown in Figure 1, a total of 13 NIH Institutes/Centers (ICs) supported SGM projects (a list of awarding NIH ICs is shown in Appendix B). NIAID, NICHD, NIDA, NIMH, and NIMHD administered the most projects, together accounting for 249 (or nearly 90%) of all SGM projects. Other ICs, including NCATS, NCI, NIA, NIAAA, NIAMS, NIDCD, NINDS, NINR, included much smaller proportions of the total projects.

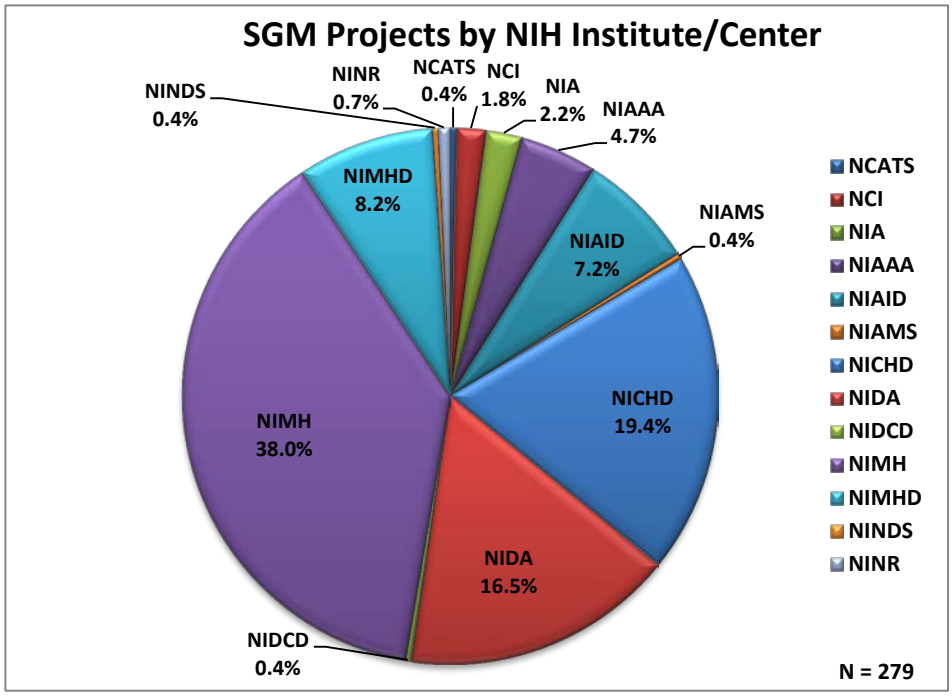

Figure 1. SGM Projects by NIH Institute or Center. *Thirteen NIH ICs support SGM projects, with the largest contribution from NIAID, NICHD, NIDA, NIMH, and NIMHD.*

Priority Research Areas Identified in the IOM Report

The IOM Report identified research priority areas to address in SGM health: *Intervention Research*, *Methodological Research*, *Demographic Research*, and research in the areas of *Social Influences*, *Inequalities in Health Care*, *Exposure to Stigma or Violence*, *Resilience*, and *Transgender-Specific Health Needs*. Manual coding was carried out to determine whether each project in the portfolio addressed one or more of these priority areas.

As shown in Figure 2, *Intervention Research* and research addressing *Social Influences* were the IOM priority areas most frequently addressed. The numbers in this figure are primarily accounted for by the

preponderance of social-behavioral interventions to prevent HIV infection. The other priority areas were less frequently addressed. Of particular note is that only 8% of all projects addressed *Transgender-Specific Health Needs*.

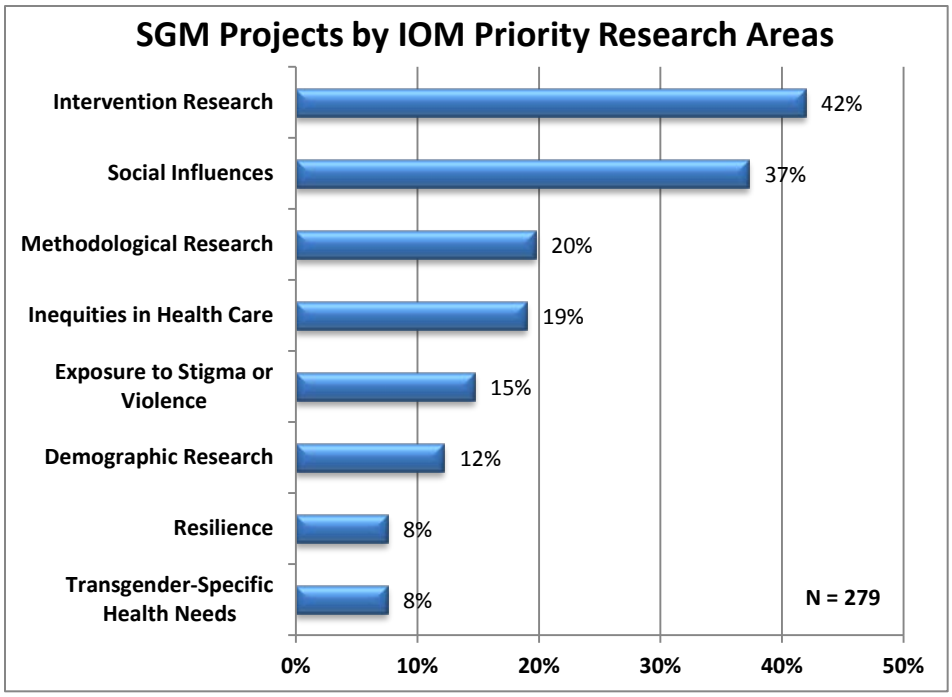

Figure 2. SGM Projects by IOM Priority Research Areas. *Intervention Research and research addressing Social Influences were the IOM priority areas most frequently addressed in NIH-supported SGM projects.*

Priority Health Conditions

This analysis is based on data from the NIH Research, Condition, and Disease Categorization (RCDC) system, which is a searchable database of funded research whose categorical spending lists are publicly accessible and which Congress directed the NIH to establish. Categories in RCDC encompass a variety of dimensions relevant to SGM health, including diseases or health conditions (e.g., diabetes), populations (e.g., pediatric), research disciplines (e.g., behavioral and social science), and research methodologies/study designs (e.g., longitudinal studies). It should be noted that some types of NIH research activities, such as LRP awards and certain training, center, and intramural research activities, are not assigned topically to RCDC categories. Projects falling within these activities that were relevant to SGM were identified by manual identification by each IC that administered the awards.

To show the overall distribution and clustering of SGM-relevant projects according to RCDC category, text maps were created using VOSviewer Version 1.5.7. Categories were mapped if they occurred at least twice across the portfolio.

As shown in Figure 3, there is a very dense cluster of projects in the *HIV/AIDS* category linked with the *Social Science* category. Not visible in the map is a slightly smaller cluster for *Prevention* that is directly underneath the *HIV/AIDS* cluster, indicating that virtually all projects related to *Prevention* focused on

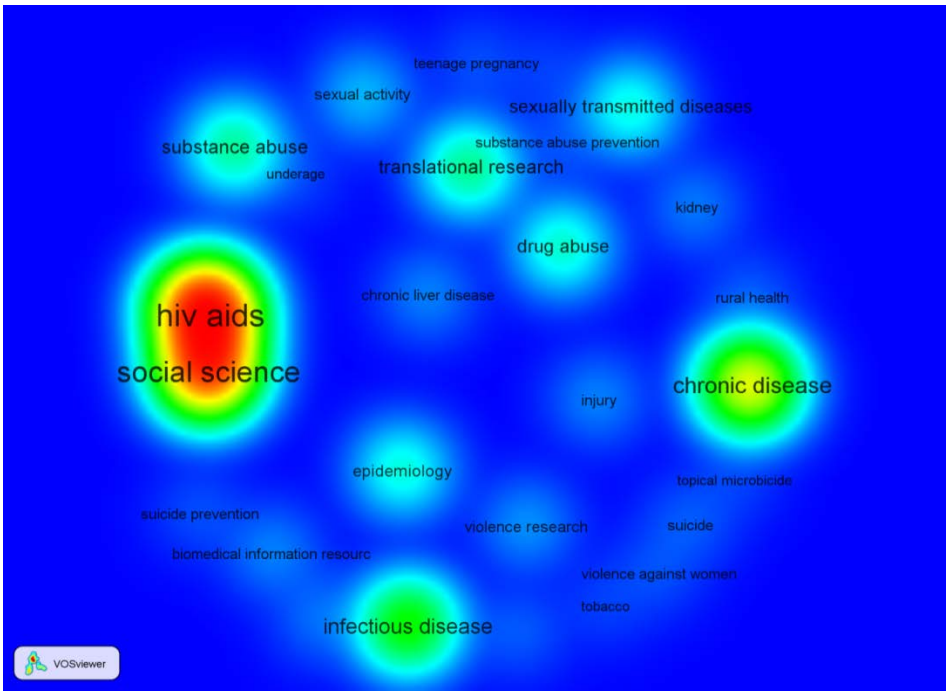

Figure 3. Map of RCDC Categories for SGM Projects. *HIV/AIDS projects, which constitute the largest cluster, are closely linked with Social Science projects; virtually all Prevention projects are focused on HIV/AIDS.*

HIV/AIDS. Another large cluster includes *Chronic Disease*, with smaller clusters in the areas of *Infectious Disease*, *Drug Abuse/Substance Abuse*, *Translational Research*, *Epidemiology*, and *Sexually Transmitted Diseases*. Other research areas are not as well represented in the portfolio, though the map includes a mix of basic and applied biomedical and social/behavioral research areas.

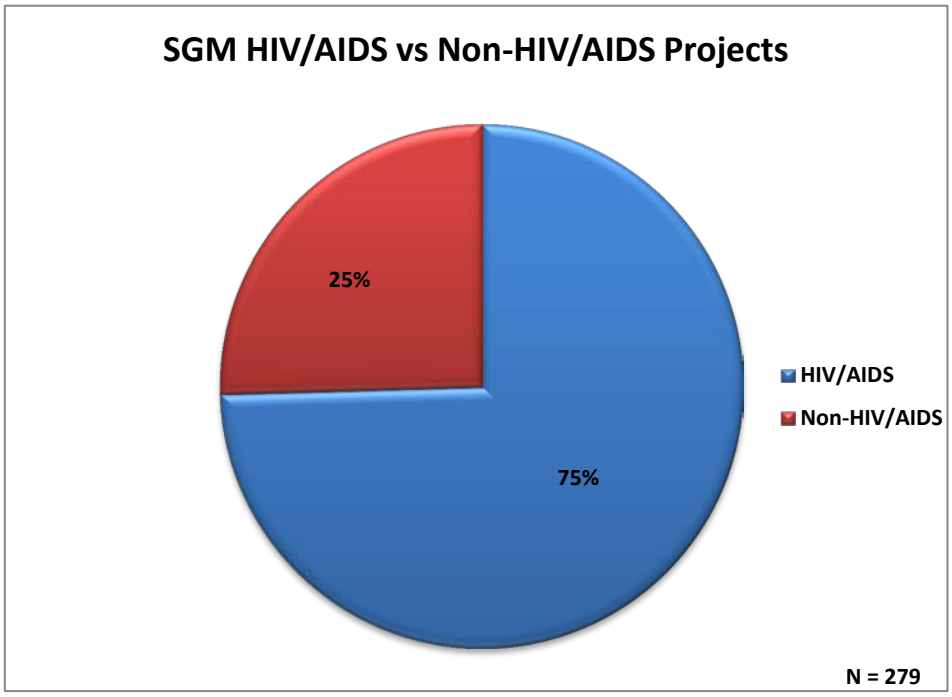

Figure 4. SGM HIV/AIDS vs. Non-HIV/AIDS Projects. *The majority of SGM projects are focused on HIV/AIDS.*

In addition to text mapping, frequencies of specific priority diseases/health conditions identified in the IOM Report or by the relevant RCDC categories were also calculated. These conditions include *Alcoholism*, *Cancer*, *Cardiovascular Disease*, *Depression*, *Eating Disorders*, *HIV/AIDS*, *Mental Health*, *Obesity*, *Sexually Transmitted Diseases/Herpes*, *Suicide*, *Reproduction/ Contraception*, *Substance Abuse*, and *Smoking*. All priority diseases/health conditions except *HIV/AIDS* were identified using RCDC categories; HIV/AIDS projects were identified through manual coding of grants.

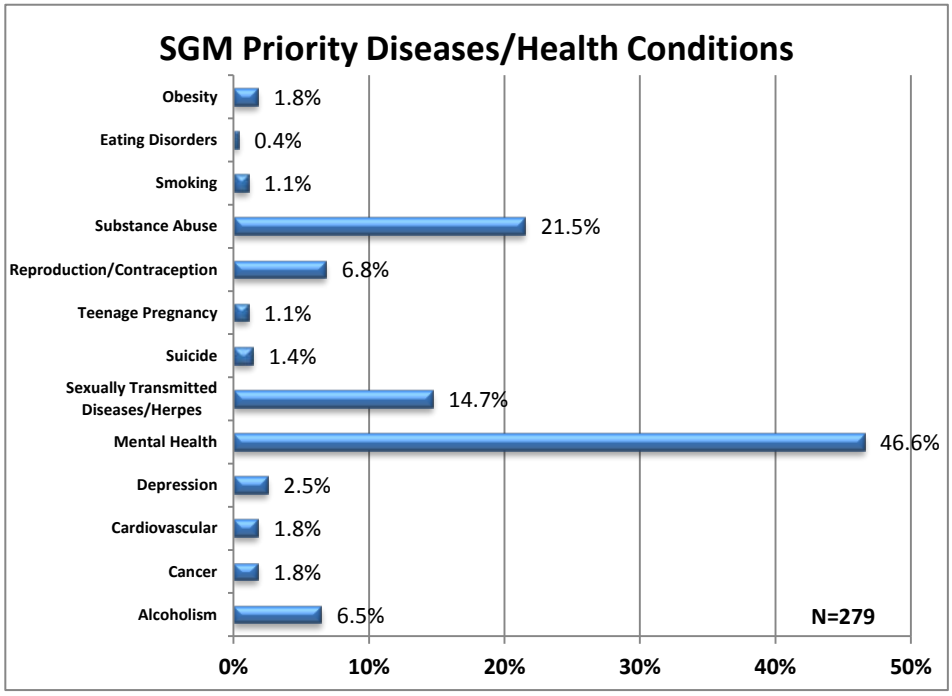

Figure 5. SGM Priority Diseases/Health Conditions. *Of those grants not concentrated on HIV/AIDS research (25% of the portfolio), Mental Health, Substance Abuse, and Sexually Transmitted Diseases/Herpes represent the most projects focused on SGM-relevant diseases/health conditions.*

As shown in Figure 4, 75% of projects had an HIV/AIDS focus. Figure 5 shows the frequency of projects addressing other SGM-relevant diseases/health conditions. With the exception of *Mental Health* (46.6%), each of the other areas is represented in less than 25% of projects. Aside from *Substance Abuse* disorders (21.5%) and *Sexually Transmitted Diseases/Herpes (excluding HIV; 14.7%)*, the other diseases and health conditions were represented by fewer than 7% of the identified SGM projects (Figure 5).

Population Focus

The target SGM populations included in each research project were identified through manual coding. As shown in Figure 6, MSM were by far the most commonly represented population (68.8%). Women (including lesbians and WSW), transgender individuals, and the I/DSD population were infrequently represented in the portfolio.

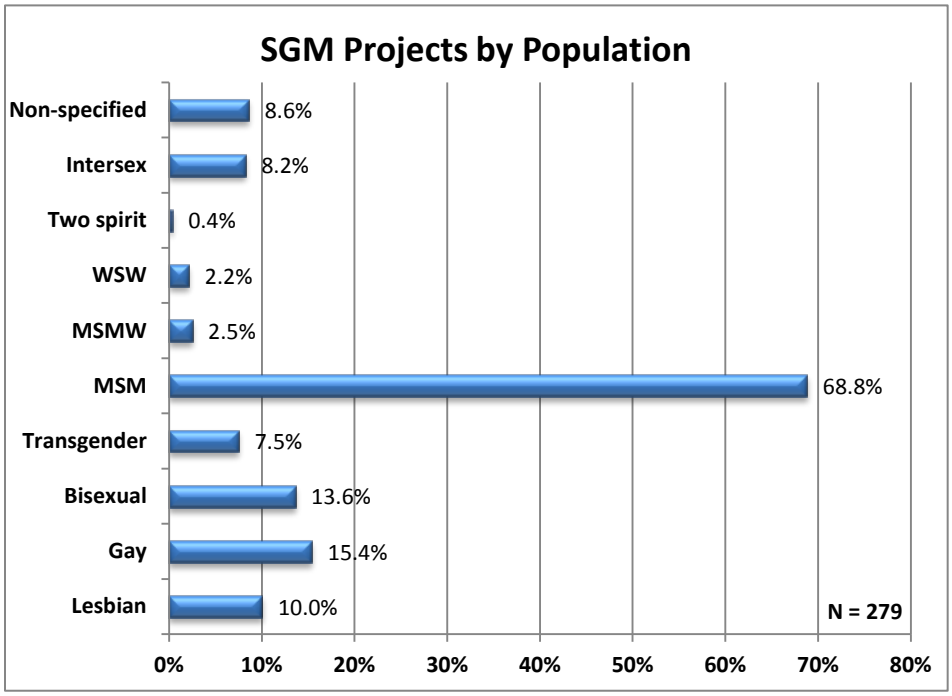

Figure 6. SGM Projects by Population. *Men who have Sex with Men (MSM) are the most commonly represented population.*

To further understand the nature of the distribution of research projects among SGM target populations, a breakdown of all the specific population groups by sex/gender was examined. As shown in Figure 7, of the 216 SGM projects that included men, the vast majority (76.9%) identified only MSM as the target population. Only small numbers of projects included groups of men identified otherwise, such as gay men, bisexual men, or men who have sex with men and women (MSMW), either alone or in combination with MSM. Clearly, for these projects, the target populations were defined more by sexual behavior than by sexual orientation or gender identity. Of

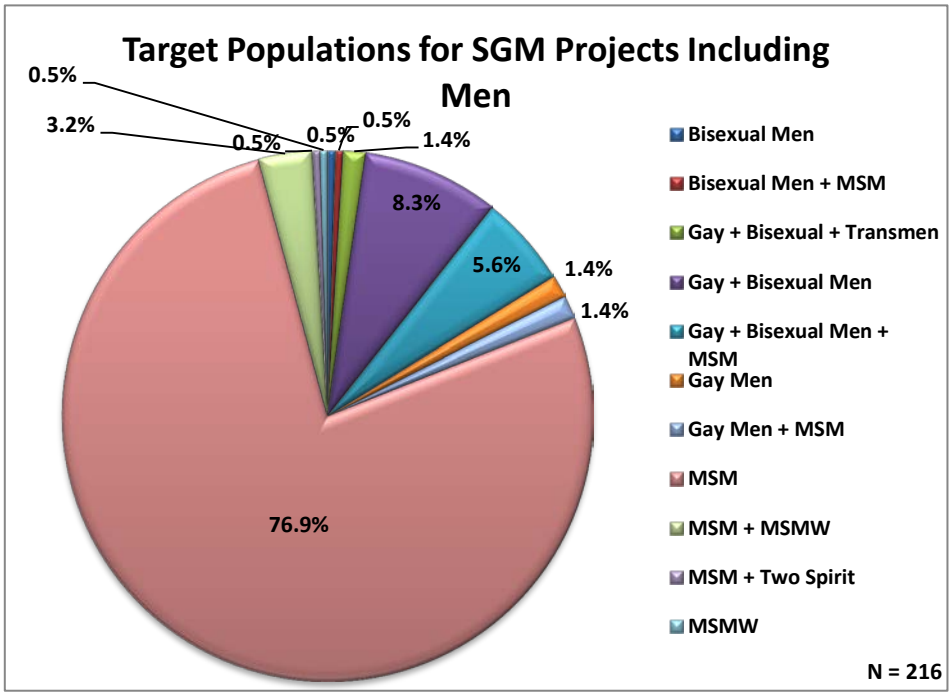

Figure 7. Target Populations for SGM Projects Including Men. *The vast majority of SGM projects that included men identified only MSM as the target population.*

particular note, only 1.4% of projects (corresponding to 3 grants) included transgender female-to-male individuals (transmen). All three of these studies targeted SGM populations as a whole for inclusion, without a specific emphasis on transgender individuals.

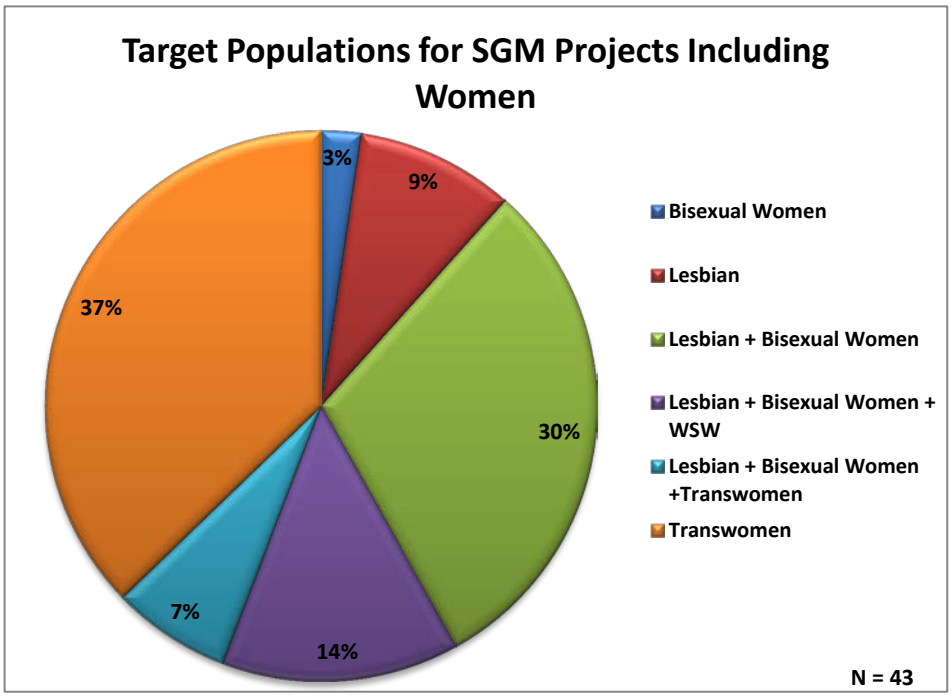

Figure 8. Target Populations for SGM Projects Including Women. *SGM projects that include women primarily focus on transgender male-to-female individuals (transwomen), either alone or in combination with lesbians and bisexual women.*

As shown in Figure 8, a reverse pattern is shown in the 43 projects including women. Inclusion of populations based on sexual orientation or gender identity is much more common than inclusion based on sexual behavior. The largest target population included is transgender male-to-female individuals (transwomen) at 44%, either alone or in combination with lesbians and bisexual women. The small number of studies addressing transgender health in the SGM portfolio was noted previously. Figures 7 and 8 also highlight a lack of studies of those born biologically female, who are represented in less than 10% of projects in the portfolio (data not shown). Further, 29 studies, or roughly 10% of the portfolio, included both SGM men and women, and these projects were primarily funded through the R01 research project activity code (data not shown).

The IOM identified a particular need for SGM research across the lifespan, identifying particular gaps with respect to youth and the elderly. To examine representation of projects across the lifespan, projects were identified according to the pediatric-related RCDC category and manually, with an elder-related keyword search (see Appendix A). Results indicate that 40% of projects had a youth focus or a combined youth/adult focus. These projects are largely characterized by HIV prevention studies in adolescent and young adult MSM.

NIH Grant, Cooperative Agreement, and Contract Mechanisms

Projects in the SGM portfolio are represented by a variety of different activity codes and funding mechanisms, including research project grants, center grants, infrastructure grants, training grants, career development awards, loan repayment awards, and intramural research projects (a glossary of NIH activity codes is provided in Appendix C). As shown in Figure 9, research projects (R) comprise the largest proportion of projects (64%), followed by research career program awards (K; 9%), loan repayment awards (L; 8%), fellowship training awards (F; 6%), and research program projects and centers (P; 5%). All other mechanisms for support comprise less than 10% of the total portfolio. A more detailed breakdown of projects and awards by activity code is provided in Appendix D.

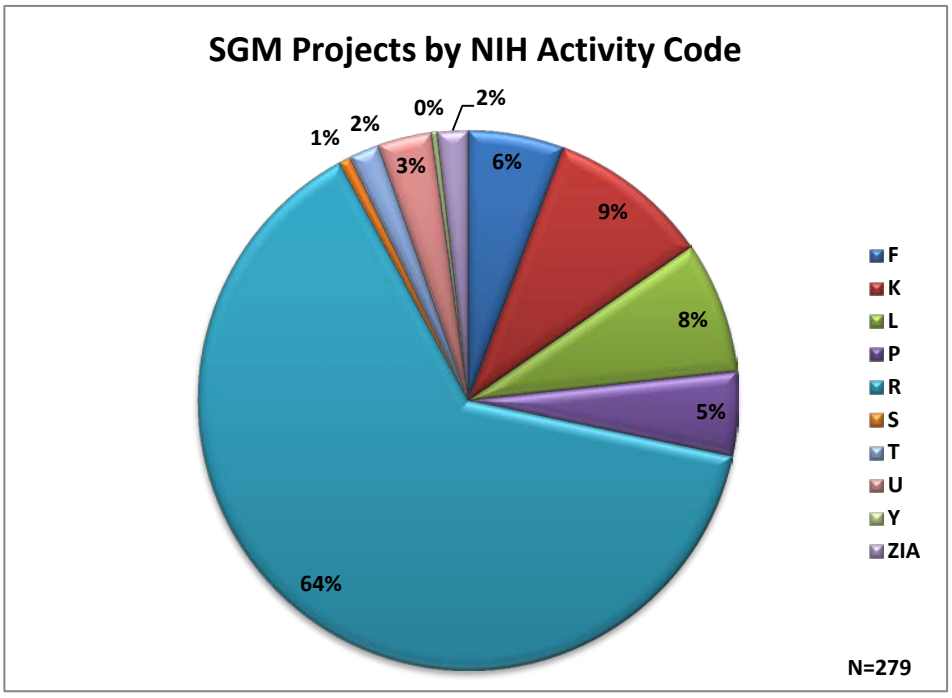

Figure 9. SGM Projects by NIH Activity Code. *Research project grants (R activities) comprise the largest proportion of SGM projects.*

NIH activity codes were examined separately for the 173 research projects (R mechanism, excluding R25 research education projects; 62% of the total portfolio) and the 75 training grants (27% of the total portfolio). Figure 10 shows the predominance of the R01 projects among the research project grants, comprising 110 (64%) of the 173 projects awarded under R activity codes.

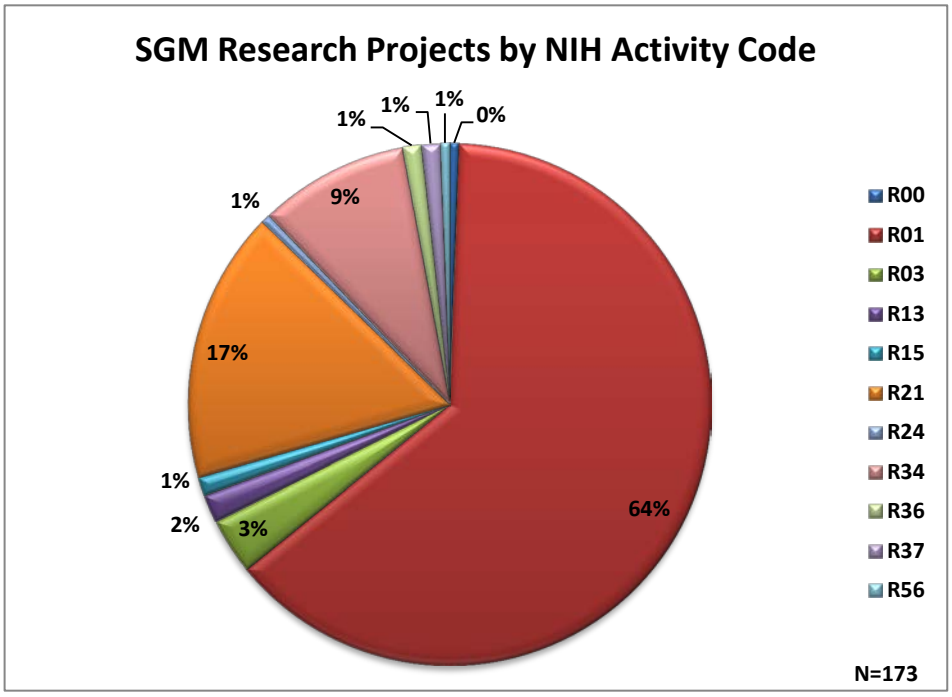

Figure 10. SGM Research Projects by NIH Activity Code. *R01 grants are the largest category of research projects.*

With respect to NIH training programs that study SGM issues, a distribution across various activities is seen (see Figure 11), with the most common being the L60 health disparities loan repayment award (23%), F31 predoctoral fellowship (19%), K01 mentored research scientist development award (14%), and K23 mentored patient-oriented research career development award (13%).

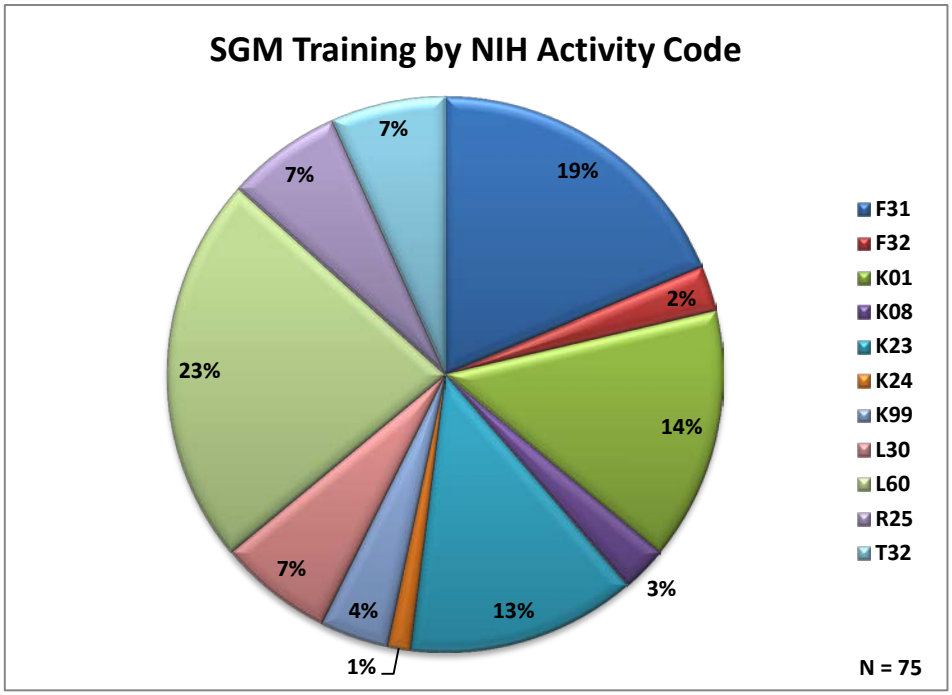

Figure 11. SGM Training by NIH Activity Code. *A range of activities is used to support training programs on SGM topics, with the largest proportion funded through the Loan Repayment Program for Health Disparities Research (L60).*

Type of Funding Opportunity Announcement (FOA)

Projects were categorized according to whether they were submitted to a program announcement (PA), PA with set-aside funding (PAS), PA with special review (PAR), or Request for Applications (RFA). Although LRP awards are technically contracts, LRP FOAs were placed in the RFA (grants) category so as to more accurately represent NIH investments in research training. As shown in Figure 12, of the 270 projects with an associated FOA (PA, PAS, and RFA), nearly 60% were submitted to a PA and just over one-quarter (26.7%) were submitted to an RFA. Nearly 14% were submitted to a PAR, while less than 1% (0.4%) was submitted to a PAS. As a caveat, intramural projects and a small number of extramural grants are not associated with a particular FOA.

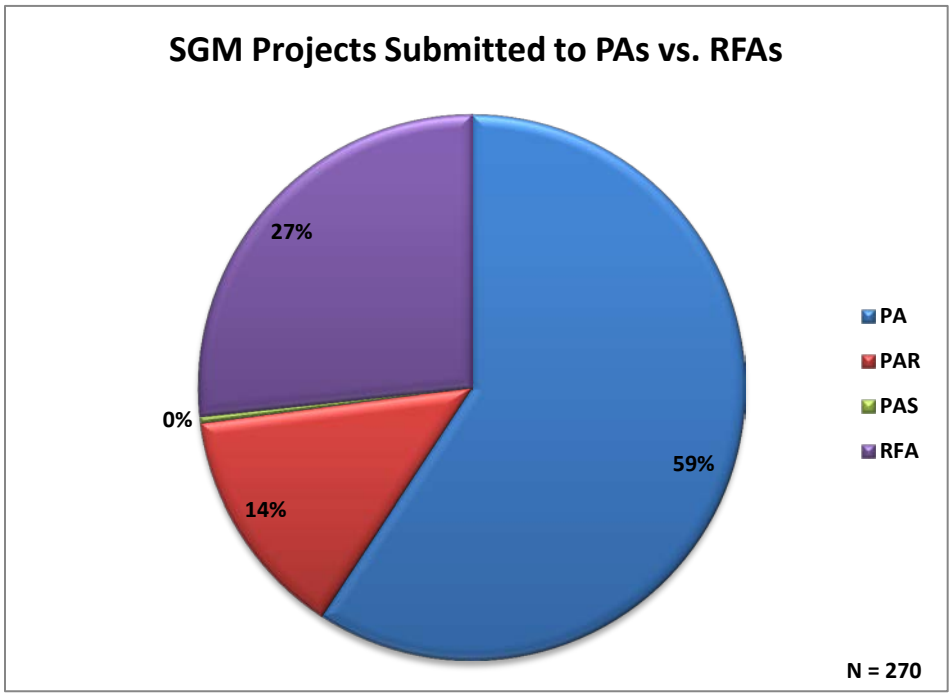

Figure 12. SGM Projects Submitted to PAs vs. RFAs. *The majority of funded SGM projects were submitted to a PA.*

FOAs were further classified into three categories: (1) *SGM-Specific*, or FOAs devoted solely to SGM populations; (2) *SGM-Relevant*, including FOAs that identify SGM populations as one of several populations of interest or that examine diseases/health conditions that disproportionately affect SGM populations; and (3) *Not SGM-Specific*, such as NIH "parent" FOAs seeking applications by specific types of activity codes.

As shown in Figure 13, the majority (68.5%) of projects were submitted to FOAs that were *Not SGM-Specific*. About one-fourth were submitted to *SGM-Relevant* FOAs. Although in theory this category could include FOAs on a variety of health conditions or target populations, in this case, all FOAs classified as *SGM-Relevant* were related to HIV/AIDS. Only 5.6% of projects were submitted to *SGM-Specific* FOAs, including PA-07-409, *Health Research with Diverse Populations* (R01 and its companion R03 and R21

PAs), and RFA-MH11-080, *Reinvigorating HIV Prevention for Men Who Have Sex with Men* (R01 and the companion R21 and R34 RFAs).

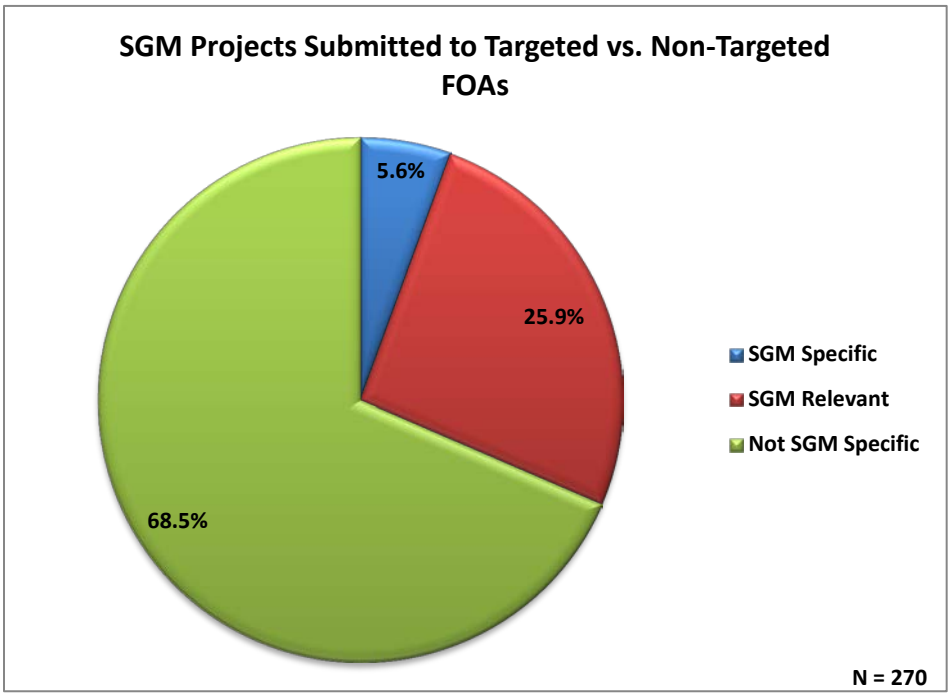

Figure 13. SGM Projects Submitted to Targeted vs. Non-Targeted FOAs. *The majority of funded SGM projects were submitted to Not SGM-Specific FOAs.*

Opportunities and Gaps in Research and Areas for Future Study

The FY 2010 SGM portfolio analysis identified a portfolio (n=232) as largely focused on HIV/AIDS with MSM, with a lesser, but substantial, emphasis on mental health and substance abuse issues, again largely with MSM. Research on other SGM-relevant health conditions and population groups was less frequently represented, and in general, the portfolio did not address many of the research gaps identified in the IOM report. The FY 2012 SGM portfolio appears to be largely similar in size (after adjusting for the addition of LRP awards, MSM, MSMW, WSW, and I/DSD projects), and with a parallel primary focus on HIV/AIDS research with MSM. When examined separately, I/DSD projects appear to demonstrate a different pattern, with the bulk being basic/pre-clinical or clinical research to understand the etiology and manifestations of these conditions. Additionally, SGM individuals who also belong to an underserved racial or ethnic population bear a double burden of stigma, stress, and more, as noted in the IOM report and Healthy People 2020. This double burden increases health disparities for these individuals.

Thus, across SGM populations, critical gaps in understanding the health needs and lived experience of SGM individuals remain. Further research is still needed in the following broad areas, as previously identified in the IOM report and the FY 2010 SGM portfolio analysis report:

- Health status, health risk (beyond HIV risk) and resilience, and healthcare utilization of SGM populations, particularly for lesbians/ bisexual women, transgender populations, and I/DSD populations

- Health consequences of SGM status, including exposure to stigma, discrimination, social exclusion, and violent victimization
- Social, emotional, and psychological development in SGM youth. There is a particular paucity of research in the NIH portfolio regarding transgender and I/DSD developmental processes
- Health issues for aging SGM populations, particularly for lesbians/ bisexual women, transgender populations, and I/DSD populations. Research is particularly needed to understand the long-term health effects of hormone therapy for transgender and I/DSD individuals
- Access to and quality of healthcare and provider cultural competence for SGM populations
- Methods of identifying and conducting research with SGM populations and the research and clinical implications of particular methods (e.g., defining populations by sexual orientation vs. sexual behavior).

Regarding the FOAs through which project applications are submitted to the NIH, it is promising to see that SGM-related applications submitted to non-SGM focused FOAs continue to successfully compete for funding. At the same time, it is not clear that projects within the NIH grant portfolio will encompass the gaps identified above if the bulk of applications are submitted to FOAs that do not identify these SGM gaps as research priorities. [Note, however, that this FY 2012 portfolio does not include applications submitted to the 2012-issued *Research on the Health of LGBTI Populations* FOA (R01, R03, R21 activities) though it does include projects submitted to the 2007 PA that was the predecessor of these announcements (*Health Research with Diverse Populations*; R01, R03, R21).]

It is possible that the FOAs referenced above will lead to an increase in projects that address the gaps and exploit the opportunities highlighted above. However, given the similarity between the FY 2010 and FY 2012 portfolios, the SGM RCC recommends that more highly targeted FOAs, preferably with budget set-asides, be issued that address both research and training (e.g., an RFA for research on health needs of transgender populations). Without this type of highly targeted solicitation and budget investment, it seems unlikely that the size or content of the NIH SGM portfolio will change significantly.

APPENDIX

Appendix A: Methods for Conducting the Portfolio Analysis

The goal of this analysis was to assess the FY 2012 NIH scientific portfolio research relevant to SGM health. No financial data were associated with this analysis. For purposes of comparison with the FY 2010 analysis, the focus was limited to awards issued in a single year, FY 2012, a limitation that provides a snapshot of this inherently dynamic scientific portfolio.

Project Identification: The methodology developed for identification of the FY 2010 portfolio was used again for the FY 2012 portfolio. In this methodology, an initial list of projects was developed using the Research, Condition, and Disease Categorization (RCDC) system and terms related to SGM health. This list was further refined through two processes. First, Boolean logic was applied to identify projects containing combinations of terms relevant to SGM health. NIH staff then inspected the descriptions of a subset of the included research projects to identify additional terms of relevance and further refine the list of projects. The RCC discussed and commented on this process as well as the terms, approaches, and parameters for conducting the analysis. The RCC agreed that the project list should include all NIH activity codes and all business areas, such as extramural grants and cooperative agreements, research and development (R&D) and other contracts, and intramural research programs.

After extensive discussion about the scientific parameters for the portfolio analysis, the committee agreed that the analysis should be limited to projects that include individuals who are lesbian, gay, bisexual, transgender, I/DSD, or related populations such as MSM (men who have sex with men) or WSW (women who have sex with women). The RCC thought it was important to include not only individuals who identify as non-conforming in sexual orientation and/or gender identity, but also individuals who engage in same-sex behaviors or otherwise may not identify with specific terminology. Although there are a number of health concerns where the risk or prevalence may be higher for individuals in SGM (or related) populations, only the projects from those disease/health portfolios that explicitly include one or more SGM or related populations as the group of interest are included in this analysis.

One example of this is the HIV/AIDS research portfolio. Although clearly SGM and related populations are disproportionately affected by HIV and AIDS, there are also studies that focus, for example, on HIV in populations thought to be heterosexual, such as HIV-positive pregnant women and their children, that the committee thought would not be appropriate to include in this analysis. The RCDC system searches for documents using only the project title, abstract, and specific aims and thus may not retrieve projects for which an investigator identifies one or more SGM populations in his or her detailed application. Only research projects that contain language in these sections describing plans to include SGM individuals were included in the initial project list. In addition, some projects, including Loan Repayment (LRP) awards and subprojects within center grants are not assigned RCDC categories. For these reasons, the list of research projects is thought to underestimate the full scope of the NIH research portfolio that includes SGM participants. Once the list was compiled using the previously defined parameters, it was distributed to the NIH ICOs' Planning and Evaluation Officers for feedback, including manual additions to the project list of SGM projects not Identified by RCDC and deletions of projects added erroneously to the list. These officers also were asked to identify which of the research areas highlighted as priorities in the IOM report were addressed in each project. The entire list was then manually examined by the RCC Portfolio Analysis Workgroup (PAW) to remove duplicates, projects identified by RCDC that did not

actually include SGM populations (e.g., as mentioned above, HIV prevention interventions with heterosexual populations), or projects that actually were not active in FY 2012.

It should be noted that only "parent" projects are included. By taking this approach, the raw number of awards is lower than the number of individual projects or studies supported by the NIH since some large networks, centers, and other types of awards supported multiple projects and subprojects that RCDC counts as a single project. In addition, even an individual R01 or other research project grant award often includes more than one study or research protocol. Administrative supplements and Revisions are other means of support for additional populations (such as SGM individuals) or new, related study questions as an adjunct to an ongoing award. Any administrative supplements directly related to SGM health were also considered with and included in the parent level project for this analysis. It should also be noted that co-funding of research projects by other ICOs is not captured in this analysis since no budgetary information was incorporated.

Population Coding: Further population coding was conducted by the RCC PAW after finalizing the project list from the ICOs. This analysis included searching each project for details regarding specific SGM populations (e.g., lesbians, gays, etc.) of interest. This task proved challenging, as this information is generally embedded in sections of an award that lack structured data elements in NIH data systems. These assessments also proved somewhat challenging due to variability in how investigators describe their target populations. The various terms used by investigators were also documented and are shown in Figures 10 and 11. Different methods were used to identify youth- or elderly-focused projects. Youth-focused projects were identified by the assignment of at least one pediatric-related RCDC category (e.g., Pediatric AIDS, Youth Violence, Teenage Pregnancy). Elderly-focused projects were identified by the assignment of the RCDC category 'Aging' or through a keyword search for 'elderly.'

FOA Coding: The classification of FOAs into the categories of *SGM-Specific*, *SGM-Relevant*, *Not SGM-Specific* was slightly different from the classification used in the FY 2010 SGM Portfolio Analysis. This earlier analysis used the category of SGM-focused FOAs, which included FOAs that were exclusively devoted to SGM populations (such as PA-07-409, *Health Research with Diverse Populations (R01)*) as well as FOAs that were not limited to SGM populations but that mentioned these groups as one of several target populations (e.g., FOAs on HIV prevention in vulnerable populations or underserved populations). This latter example was classified as *SGM-Relevant* rather than *SGM-Specific* according the FY 2012 definition. This more restrictive classification is likely to at least partially explain the smaller proportion of projects submitted under *SGM-Specific* FOAs (5.6%) in the FY 2012 portfolio than SGM-Focused FOAs in FY 2010 (16.2%).

Appendix B: NIH Institutes, Centers, and Offices Represented on the NIH SGM RCC *

FIC	Fogarty International Center
NCCAM	National Center for Complementary and Integrative Health
NCI	National Cancer Institute
NEI	National Eye Institute
NHGRI	National Human Genome Research Institute
NHLBI	National Heart, Lung, and Blood Institute
NIA	National Institute on Aging
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NIAID	National Institute of Allergy and Infectious Diseases
NICHD	*Eunice Kennedy Shriver* National Institute of Child Health and Human Development
NIDA	National Institute on Drug Abuse
NIDCD	National Institute on Deafness and Other Communication Disorders
NIDCR	National Institute of Dental and Craniofacial Research
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIEHS	National Institute of Environmental Health Sciences
NIGMS	National Institute of General Medical Sciences
NIMH	National Institute of Mental Health
NIMHD	National Institute on Minority Health and Health Disparities
NINDS	National Institute on Neurological Disorders and Stroke
NINR	National Institute of Nursing Research
OD/IMOD	Office of the Director, Immediate Office of the NIH Director
OD/OAR	Office of the Director, Office of AIDS Research
OD/OBSSR	Office of the Director, Office of Behavioral and Social Sciences Research
OD/ODP	Office of the Director, Office of Disease Prevention
OD/OEDI	Office of the Director, Office of Equity, Diversity, and Inclusion
OD/OER	Office of the Director, Office of Extramural Research
OD/OIR	Office of the Director, Office of Intramural Research
OD/ORWH	Office of the Director, Office of Research on Women's Health
OD/OSC	Office of the Director, Office of Strategic Coordination

*At time of analysis

Appendix C: Glossary of NIH Activity Codes

F31	Predoctoral Individual National Research Service Award (NRSA)
F32	Postdoctoral Individual National Research Service Award (NRSA)
K01	Research Scientist Development Award - Research & Training
K08	Clinical Investigator Award (CIA)
K23	Mentored Patient-Oriented Research Career Development Award
K24	Midcareer Investigator Award in Patient-Oriented Research
K99	Career Transition Award
L32	Loan Repayment Program for Clinical Researchers from Disadvantaged Backgrounds
L60	Loan Repayment Program for Health Disparities Research
P01	Research Program Projects
P20	Exploratory Grants
P30	Center Core Grants
P60	Comprehensive Center
R00	Research Transition Award
R01	Research Project Grants
R03	Small Research Grants
R13	Conference Grants
R15	Academic Research Enhancement Awards (AREA)
R21	Exploratory/Developmental Grants
R24	Resource-Related Research Projects
R25	Education Projects
R34	Planning Grant
R36	Dissertation Award
R37	Method to Extend Research in Time (MERIT) Award
R56	High Priority, Short Term Project Award
SC2	Pilot Research Project
T32	Institutional National Research Service Award (NRSA)
U01	Research Project--Cooperative Agreements
U19	Research Program--Cooperative Agreements
U24	Resource-Related Research Projects--Cooperative Agreements
UM1	Research Project with Complex Structure Cooperative Agreement
Y01	Inter/Intra-Agency Agreements
ZIA	Intramural Research

Appendix D: NIH SGM Projects by Activity Code

Activity Code	Number of SGM Projects
F31	14
F32	2
K01	11
K08	2
K23	10
K24	1
K99	3
L30	5
L60	17
P01	2
P20	1
P30	9
P60	2
R00	1
R01	110
R03	6
R13	3
R15	2
R21	29
R24	1
R25	5
R34	16
R36	2
R37	2
R56	1
SC2	2
T32	5
U01	5
U19	2
U24	1
UM1	1
Y01	1
ZIA	5

Appendix E: NIH SGM Research Coordinating Committee Roster

Rashada C. Alexander, Ph.D. Special Assistant to the Principal Deputy Director of NIH Immediate Office of the Director Office of the Director, NIH	**Susannah Allison, Ph.D.** Division of AIDS Research National Institute of Mental Health, NIH	**Carl Baker, M.D., Ph.D.** National Institute on Arthritis and Musculoskeletal Disorders, NIH
Eddie Byrnes, Ph.D. Office of Strategic Coordination Office of the Director, NIH	**Paul Cotton, Ph.D., R.D.,*** National Institute of Nursing Research	**Sandeep Dayal, Ph.D.** Health Science Policy Analyst Office of Scientific Program and Policy Analysis National Institute of Diabetes & Digestive & Kidney Diseases, NIH
Bill Elwood, Ph.D. Office of Behavioral and Social Sciences Research Office of the Director, NIH	**Courtney Ferrell Aklin, Ph.D.** Program Director Office of Special Programs in Diversity National Institute of Neurological Disorders and Stroke, NIH	**Robert Freeman, Ph.D.** National Institute on Alcohol Abuse and Alcoholism, NIH
Simone Glynn, M.D., M.Sc., M.P.H. Chief, Transfusion Medicine and Cellular Therapeutics Branch Division of Blood Diseases and Resources National Heart Lung and Blood Institute, NIH	**William C. Grace, Ph.D.** Coordinator, Behavioral and Social Science Research Office of AIDS Research Division of Program Coordination, Planning, and Strategic Initiatives, Office of the Director, NIH	**Sue Hamann, Ph.D.** National Institute on Dental and Craniofacial Research, NIH
Shoshana Kahana, Ph.D. National Institute on Drug Abuse, NIH	**Rebecca Liddell Huppi, Ph.D.** Program Director AIDS Cancer Clinical Program Office of HIV and AIDS Malignancy Office of the Director, National Cancer Institute, NIH	**Enid Light, Ph.D.** Division of International Training and Research Fogarty International Center, NIH
Sharon L. Milgram, Ph.D. Director, NIH Office of Intramural Training & Education Office of Intramural Research Office of the Director, NIH	**Amy Mistretta, M.P.H.** Office of Research on Women's Health Division of Program Coordination, Planning, and Strategic Initiatives, Office of the Director, NIH	**Catherine Nagy, M.A.** Senior Public Health Analyst Office of Planning, Analysis, and Evaluation National Institute on Aging, NIH
Susan F. Newcomer, Ph.D. Statistician/Demographer Demographic and Behavioral Sciences Branch Center for Population Research *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, NIH	**Richard Okita, Ph.D.** National Institute of General Medical Sciences, NIH	**Kathleen M. O'Leary, M.S.W.*** Acting Chief, Women's Program Office of Research on Disparities and Global Mental Health National Institute of Mental Health, NIH

Susanne Olkkola, M.Ed., M.P.A. Office of Disease Prevention Office of the Director, NIH	**Karen L. Parker, Ph.D., M.S.W.** Acting Chief, Science Planning and Coordination Branch and Women's Health Officer Office of Science Planning and Assessment National Cancer Institute, NIH	**Lita Proctor, Ph.D.** National Human Genome Research Institute, NIH
William Quattlebaum National Institute of Environmental Health Sciences, NIH	**James Raber** National Eye Institute, NIH	**Philip O. Renzullo, Ph.D., M.P.H.** Deputy Branch Chief, Vaccine Clinical Research Branch Program Officer, Vaccine Research Program Division of Acquired Immunodeficiency Syndrome (DAIDS) National Institute of Allergy and Infectious Diseases, NIH
Alberto Rivera-Rentas, Ph.D.† National Institute on Deafness and Other Communication Disorders, NIH	**Mark Rubert, Ph.D.** Scientific Review Officer Behavioral and Social Consequences of HIV/AIDS Scientific Review Group Center for Scientific Review, NIH	**Jeff Schulden, M.D.** Epidemiology Research Branch National Institute on Drug Abuse, NIH
Tara A. Schwetz, Ph.D. Special Assistant to the Principal Deputy Director of NIH Immediate Office of the Director Office of the Director, NIH	**Lana Shekim, Ph.D.** Program Director Voice and Speech Programs Division of Scientific Programs National Institute on Deafness and Other Communication Disorders, NIH	**Albert Smith** Office of Equity, Diversity, and Inclusion Office of the Director, NIH
Nathan Stinson, Jr., Ph.D., M.D., M.P.H.** Director, Division of Extramural Scientific Programs, National Institute on Minority Health and Health Disparities, NIH	**Denise Stredrick, Ph.D.** Health Science Policy Analyst Office of Disease Prevention Division of Program Coordination, Planning, and Strategic Initiatives, Office of the Director, NIH	**Francisco Sy, M.D., Dr.P.H.** Director, Office of CBPR & Collaborations National Institute on Minority Health and Health Disparities, NIH
Meredith D. Temple-O'Connor, Ph.D. NIH Inclusion Policy Officer and LGBT Research Coordinator Office of Extramural Research, Office of the Director, NIH	**Elizabeth Wehr, J.D.**** Senior Public Health Analyst Office of Science Policy, Analysis and Communication *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, NIH	**Vanessa White, M.P.H.** Program Analyst Office of AIDS Research Office of the Director, NIH
John Williamson, Ph.D. National Center on Complementary and Integrative Health, NIH	**Shimian Zou, Ph.D.** National Heart Lung and Blood Institute, NIH	

*Has moved to another position and/or rotated off the committee

**Committee Co-Chairs

†Formerly at National Center for Complementary and Integrative Health, NIH