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Introduction

The National Institutes of Health (NIH) is comprised of 27 Institutes and Centers (ICs), as well as Offices. Each has its own specific research agenda, often focusing on particular disease areas or health conditions. All but three of these components receive their funding directly from Congress, and administer their own budgets. NIH leadership plays an active role in shaping the agency’s research planning and activities. The Office of the Director (OD) is the central office responsible for setting policy for the NIH and for planning, managing, and coordinating the programs and activities of all the NIH components. The Sexual & Gender Minority Research Office (SGMRO) resides within the Division of Program Coordination, Planning, and Strategic Initiatives in the OD.

The SGMRO coordinates sexual and gender minority (SGM) related research and activities by working directly with the NIH ICs and Offices. The Office was established in September 2015 and serves as a resource for the NIH as well as the extramural research and stakeholder communities.

The NIH strives to support a range of biomedical, clinical, behavioral, and social science research to improve and protect the health of SGM populations. These populations include individuals who identify as lesbian, gay, bisexual, transgender, or intersex (LGBTI), and individuals who do not self-identify with one of these terms but whose sexual orientation, gender identity, or reproductive development varies from traditional, societal, cultural, or physiological norms. The NIH adopted the term “SGM” to be fully inclusive of these diverse populations, whose health is understudied and who share and differ in their health concerns. This report summarizes NIH’s investment in SGM research for Fiscal Year (FY) 2016.
Health Needs of SGM Populations

Mounting evidence indicates that SGM populations have less access to health care and higher burdens of certain diseases, such as depression, cancer, and HIV/AIDS. However, the extent and causes of health disparities are not fully understood, and research on how to close these gaps is lacking. In addition, SGM populations have unique health concerns, access to, and interactions with the health care system. The NIH recognizes that more research is needed to understand these challenges.

Progress has been made in recent years for SGM populations, with gains in legal rights and changing social attitudes. Stigmatization, hate-violence, and discrimination, however, are still major barriers to the health and well-being of SGM populations.

On October 6, 2016, the NIH designated sexual and gender minorities as a health disparities population for research. This designation builds on previous steps taken by the NIH to advance SGM health research. In 2011, the Institute of Medicine (now The National Academies of Sciences, Engineering, and Medicine) published an NIH-commissioned report on LGBT health issues. In response to the report recommendations, the NIH developed an SGM Research Strategic Plan that spans the agency and established the SGMRO to help eliminate barriers to conducting SGM-related research. The health disparities population designation marks an important and necessary step in realizing NIH’s mission to advance the health of all Americans.

Methods

The 334 projects identified in NIH’s RePORTER that comprise the NIH SGM portfolio for FY 2016 were selected by using NIH’s Research, Condition, and Disease Categorization (RCDC) reporting tool. “Sexual and Gender Minorities” was added in FY 2015 to the official list of the currently reported 233 RCDC categories. As a result, this estimate of SGM projects and spending constitutes the second report of those data. RCDC uses text data mining (categorizing and clustering words and multiword phrases), in conjunction with a list of concepts and synonyms selected by NIH scientific experts, to define research categories. Reflecting the NIH’s inclusive approach to SGM health research, the RCDC definition includes lesbian, gay, bisexual, and transgender populations as well as many others. For example, men who have sex with men (who may not identify as gay or bisexual), two-spirit populations, and those with differences/disorders of sex development (DSD), sometimes described as intersex, are included in the NIH definition of SGM.
The 2016 Portfolio Analysis

According to RePORTER, a total of 334 SGM-related projects were funded in FY 2016. The total dollar amount of SGM-related funding was $174,989,793. Key findings from the 2016 portfolio analysis include the following:

- Three NIH Institutes accounted for 68 percent of SGM funding;
- Nearly three-quarters of all projects were in some way related to HIV/AIDS; and
- A smaller proportion of projects were dedicated to disease conditions other than HIV/AIDS, also known to disproportionately impact SGM populations.

In FY 2016, there was a 9 percent increase in the number of projects from FY 2015 (from 301 to 334). Also, there was an increase in the value of the portfolio of approximately $13,692,593 (8%) from FY 2015 to FY 2016. The total value of projects in FY 2016 was $174,989,793, compared to $161,297,200 in FY 2015.

RCDC funding amounts are an estimate, based on the SGM fingerprint, text mining approach, and attribution of all grant funds to a given category. The RCDC SGM category has been in use for 2 years; therefore, only 2-year comparisons are reported.
The total number of SGM projects administered by the NIH in FY 2016 was 334. These projects were administered by 15 of the 24 grant-making ICs and the Office of the Director. The majority of projects, 257 of 334 (77%), were administered by the National Institute of Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), the National Institute of Allergy and Infectious Diseases (NIAID), and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The remaining 23 percent of projects were administered by 12 other ICs and the Office of the Director. For a list of all NIH ICs and Offices, see Appendix A.

**FY 2016, Number of SGM-related Projects by NIH Institute/Center/Office (N=334)**

<table>
<thead>
<tr>
<th>Institute/Center/Office</th>
<th>Projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIMH</td>
<td>85</td>
</tr>
<tr>
<td>NIDA</td>
<td>74</td>
</tr>
<tr>
<td>NIAID</td>
<td>49</td>
</tr>
<tr>
<td>NICHD</td>
<td>49</td>
</tr>
<tr>
<td>NIAAA</td>
<td>16</td>
</tr>
<tr>
<td>NIMHD</td>
<td>16</td>
</tr>
<tr>
<td>NCI</td>
<td>13</td>
</tr>
<tr>
<td>NIA</td>
<td>7</td>
</tr>
<tr>
<td>NINR</td>
<td>7</td>
</tr>
<tr>
<td>NIDDK</td>
<td>6</td>
</tr>
<tr>
<td>NIGMS</td>
<td>4</td>
</tr>
<tr>
<td>FIC</td>
<td>2</td>
</tr>
<tr>
<td>NHLBI</td>
<td>2</td>
</tr>
<tr>
<td>OD</td>
<td>2</td>
</tr>
<tr>
<td>NIBIB</td>
<td>1</td>
</tr>
<tr>
<td>NIEHS</td>
<td>1</td>
</tr>
</tbody>
</table>
The total number of funding for SGM-related research in FY 2016 was $174,989,793. The same ICs that fund the most projects also administer the most funding. NIAID, NIDA, NIMH, and NICHD together accounted for 80 percent of SGM funding in FY 2016.

*Other includes NIA, NINR, NIEHS, NIDDK, NHLBI, OD, FIC, and NIBIB.*
The majority of SGM projects (73%) pertain in some way to HIV/AIDS. This reflects the historical and contemporary, disproportionate incidence and prevalence of HIV/AIDS among SGM persons, particularly men who have sex with men and transgender women.

FY 2016, Percentage of SGM Projects Related to HIV/AIDS (N=334)

- **Non-HIV/AIDS**: 27%
- **HIV/AIDS**: 73%
SGM Projects by Disease Area/Health Condition

Although the majority of SGM projects are in some way related to HIV/AIDS, there is a wide range of other disease areas and health conditions that are addressed in SGM-related projects funded by the NIH in FY 2016. Projects focused on mental health, substance abuse, sexually transmitted diseases/herpes, and cancer were the four most common types of projects funded, aside from HIV/AIDS. Other projects addressed alcoholism, alcohol use and health, contraception/reproduction, depression, obesity, suicide, smoking, eating disorders, and teenage pregnancy. Categories reported below are not mutually exclusive and represent other areas of research within the RCDC categorization system.

FY 2016, Proportion of SGM Projects by Disease Area/Health Condition (N=334)
SGM Funding by Disease Area/Health Condition

The amount of funding in each of the disease areas/health conditions correspond roughly to the number of grants in those areas. Funding in HIV/AIDS was slightly more than $141 million. Funding for SGM research in substance abuse, mental health, cancer, and sexually transmitted diseases/herpes all exceeded $20 million. Categories reported below are not mutually exclusive and represent other areas of research within the RCDC categorization system. Therefore, dollars can be counted towards more than one disease area or health condition.

FY 2016, Total Grant Dollars by SGM Disease Area/Health Condition (Total: $174,989,793)
Proportion of Projects by NIH Grant Mechanism

The Research Project (R) mechanism constituted the majority (61%) of grants, followed by Research Career Activities (K; 12%), and Cooperative Agreements (U; 12%). Program Projects and Center Grants (P) and Fellowships (F), at 7 percent and 6 percent, respectively, together constitute 13 percent of the SGM portfolio, while Intramural Projects (Z), Training Grants (T), and Institution Training and Director Program Projects (D) grants constituted the remaining 9 projects, or just under 3 percent of the total portfolio.

FY 2016, Proportion of Projects by Grant Mechanism (N=334)
Proportion of SGM-Related Projects by Type of Training/Career Funding Mechanism

Research Scientist Development Awards (K01), Pre-doctoral Fellowships (F31), and Mentored Patient-Oriented Research Career Development Awards (K23) constituted more than three out of four (77%) projects pertaining to training and career development in FY 2016. In FY 2015, the total number of training-related awards was 49, compared to 60 in FY 2016.

FY 2016, Projects with Training/Career Funding Mechanism (N=60)

- Midcareer Investigator Award in Patient-Oriented Research (K24), 1
- Academic/Teacher Award (K07), 1
- Clinical Investigator Award (K08), 4
- Research Scientist Development Award (K01), 19
- Predoctoral Fellowship (F31), 14
- Postdoctoral Fellowship (F32), 6
- Mentored Patient-Oriented Research Career Development Award (K23), 13
- Career Transition Award (K99), 1
- Institutional Training (T32), 1
Proportion of Projects With New/Early Investigators

Of the 120 R01s and 1 DP2 grant, 7 (6%) were either early investigator awards – defined as the first 10 years since the receipt of a terminal degree – or were new investigators to the NIH, not having been a Principal Investigator on a previous grant. Please note that this indicates early stage and new investigators (ESI and NI respectively) at the time of their initial application, and does not reflect all investigators in the portfolio who were early or new at the time that the projects were initiated.

Among the 121 FY 2016 R01-equivalent competing grant awards falling under the SGM (SGM/ LGBT*) RCDC category, there were 7 awards flagged as NI, 4 of which also were flagged as ESI.

FY 2016, Proportion of Projects with New/Early Investigator (N=121)
SGM funding was provided to organizations in 26 states and Washington, DC. The total number of projects represented is 320; 14 SGM projects were funded in other countries. The states with the largest number of projects (more than 35 each) were California, Illinois, and New York. Please note that this map indicates the location of the funded institution and not necessarily where activity on a project takes place.
Projects are funded through institutions, which are located across the country, and sometimes the world. In fact, all of the institutions below are located in just over half (26) of the states in the United States. This illustration provides a visual representation of the institutions where the largest number of projects are located in each of those states, or countries. The project counts in this map are unique and only counted once. The area of the polygon is proportional to the number of awards.

**SGM Projects by Institution**

Projects are funded through institutions, which are located across the country, and sometimes the world. In fact, all of the institutions below are located in just over half (26) of the states in the United States. This illustration provides a visual representation of the institutions where the largest number of projects are located in each of those states, or countries. The project counts in this map are unique and only counted once. The area of the polygon is proportional to the number of awards.

**FY 2016, SGM Projects by Institution (N=334)**
The SGM Portfolio can be characterized in terms of the categories to which a research project belongs. In this illustration, an automated system uses RCDC indexing terms to group projects into various categories. These categories may be the focus of the research, such as “substance abuse” or simply related to the research in some way, such as the case with “behavioral and social science.” The figure below illustrates all of the categories to which any of the projects in the SGM portfolio belong: the majority of projects belong to at least one category in addition to SGM, listed here as “SGM/LGBT*.” The area of the polygon is proportional to the number of awards.
Conclusion

In summary, the NIH acknowledges that HIV/AIDS remains an important area of research for the SGM portfolio, as the single largest funded area. Yet, the impact of other disease areas and health conditions on SGM populations is not fully understood. Modest increases in funding (in terms of total amounts) will help, but a substantial infusion of funding, support for new researchers, and applications for new research projects are needed to launch the SGM portfolio from a nascent topic of study to a robust research field.
Appendix

NIH Institutes, Centers, and Offices

**NIH Offices**
- NIH Office of the Director (OD) *

**NIH Institutes**
- National Cancer Institute (NCI)
- National Eye Institute (NEI)
- National Heart, Lung, and Blood Institute (NHLBI)
- National Human Genome Research Institute (NHGRI)
- National Institute on Aging (NIA)
- National Institute on Alcohol Abuse and Alcoholism (NIAAA)
- National Institute of Allergy and Infectious Diseases (NIAID)
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
- National Institute of Biomedical Imaging and Bioengineering (NIBIB)
- *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)
- National Institute on Deafness and Other Communication Disorders (NIDCD)
- National Institute of Dental and Craniofacial Research (NIDCR)
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- National Institute on Drug Abuse (NIDA)
- National Institute of Environmental Health Sciences (NIEHS)
- National Institute of General Medical Sciences (NIGMS)
- National Institute of Mental Health (NIMH)
- National Institute on Minority Health and Health Disparities (NIMHD)
- National Institute of Neurological Disorders and Stroke (NINDS)
- National Institute of Nursing Research (NINR)
- National Library of Medicine (NLM)

**NIH Centers**
- NIH Clinical Center (CC)
- Center for Information Technology (CIT)
- Center for Scientific Review (CSR)
- Fogarty International Center (FIC)
- National Center for Advancing Translational Sciences (NCATS)
- National Center for Complementary and Integrative Health (NCCIH)

* The Office of the Director is comprised of multiple offices.