NIH FY 2016-2020 Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities

NATIONAL INSTITUTES OF HEALTH SEXUAL AND GENDER MINORITY RESEARCH COORDINATING COMMITTEE

NATIONAL INSTITUTES OF HEALTH

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Introduction

The National Institutes of Health (NIH) developed this Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities (SGM) after substantive analysis and integration of portfolio analyses, community input, inter- and intra-agency collaborations, and recommendations from the NIH-commissioned Institute of Medicine report released in 2011. As noted by NIH Director Francis Collins, better understanding is needed of SGM health needs, how they change throughout the lifespan, and how they are affected by other factors such as race, ethnicity, and socioeconomic status.[1]

The NIH SGM Strategic Plan promotes and supports the advancement of basic, clinical, and behavioral and social sciences research to improve the health of people whose sexual orientations, gender identities/expressions, and/or reproductive development vary from traditional, societal, cultural, or physiological norms. In each of these areas, NIH will coordinate with NIH intramural and extramural program directors and researchers to ensure the advancement of SGM-focused research efforts.

The NIH SGM Research Coordinating Committee (RCC) anticipates that this 5 year plan, which will cover the years 2016-2020, will provide the NIH with a framework for progress in this area, and that the research that results from this plan will lay a foundation for improved health and well-being amongst a group of diverse individuals whose health needs have not traditionally received strong attention from the research community.

A Note on Terminology

The terms that individuals and groups use to refer to themselves often change or evolve over time; in contrast, a Federal agency requires uniform terminology for reports to Congress and the American people. To remain inclusive yet consistent, NIH has opted to use "Sexual and Gender Minority," 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).

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[1] Collins, Francis. *Plans for Advancing LGBT Health Research*. January 2013.

Background

Individuals from sexual and gender minority (SGM) populations are at increased risk for and experience higher rates of certain diseases. For example, depression and anxiety disorders are 1.5 times higher among SGM than non-SGM populations.[2] HIV/AIDS continues to exact a severe toll on men who have sex with men (MSM), with black and Latino men being disproportionately affected. Among MSM in 2013, African Americans accounted for the highest estimated percentage of persons diagnosed with AIDS (40%), followed by whites (32%) and Hispanics/ Latinos (23%).[3] Additionally, rates of certain types of cancer are higher in SGM populations. Fourteen percent of lesbians and 17.6% of bisexual women have reported ever having had any cancer, compared with 11.9% for heterosexual women. Bisexual women have the highest rate of breast cancer at 8.4%.[4] Lesbians have significantly higher 5-year and lifetime risk for developing breast cancer.[5] Men who have sex with men have a higher prevalence of anal cancer than men in the general population.[6]

Lesbian and bisexual women over age 50 have a higher risk for cardiovascular disease and prevalence of myocardial infarction than heterosexual women over age 50.[7,8] Bisexual women have a higher prevalence of diabetes than heterosexual women.[8,9]

Limited research suggests that transgender women and men may experience negative health outcomes as a result of long-term hormone use. Transgender women using estrogen therapy, with or without anti-androgen therapy, have lower blood pressure. Transgender men on testosterone therapy have increased body mass index. About 6% of transsexual women have a thromboembolic event and 6% had cardiovascular problems after long-term hormone treatment averaging 11.3 years.[10,11]

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[2] King M, et al. Systematic review of mental disorder, suicide, and deliberate self harm in lesbian, gay, and bisexual people. [Internet]. 2008 [cited 2013 Mar 10]. First published in A BioMed Central Psychiatry, 8(70):1-17.

[3] Ward BW, et al. Sexual orientation and health among U.S. adults: National Health Interview Survey, 2013. National health statistics reports; no 77. Hyattsville, MD: National Center for Health Statistics. 2014.

[4] Valanis BG, et al. Sexual orientation and health: comparisons in the women's health initiative sample. Arch Fam Med. 2000 Sep-Oct; 9(9):843-53.

[5] Kerr DL, Ding K, Thompson AJ. A comparison of lesbian, bisexual, and heterosexual female college undergraduate students on selected reproductive health screenings and sexual behaviors. Women's Health Issues: November – December 2013, Vol.23, No. 6:e347-55.

[6] Centers for Disease Control and Prevention Fact Sheets. HIV among African American Gay and Bisexual Men

[7] Fredriksen-Goldsen KI, et al. Health Disparities Among Lesbian, Gay, and Bisexual Older Adults: Results From a Population-Based Study. American Journal of Public Health: October 2013, Vol. 103, No. 10, pp. 1802-1809.

[8] California Health Interview Survey. CHIS 2007 Adult Public Use File. Los Angeles, CA: UCLA Center for Health Policy Research, January 2007.

[9] Dilley JA, et al. Demonstrating the importance and feasibility of including sexual orientation in public health surveys: health disparities in the Pacific Northwest. Am J Public Health. 2010 Mar;100 (3):460-7.

[10] Deutsch, Madeline B.; Bhakri, Vipra; Kubicek, Katrina MA. Effects of Cross-Sex Hormone Treatment on Transgender Women and Men. Obstetrics & Gynecology: March 2015 - Volume 125 - Issue 3 - p 605–610.

[11] Wierckx K, et al. Long-term evaluation of cross-sex hormone treatment in transsexual persons. The Journal of Sexual Medicine. October 2012 Vol. 9, No.10, pp.2641-2651.

Experts in the field of SGM health research agree that there are important gaps in the published literature on SGM health. Research has not adequately examined subpopulations, particularly racial and ethnic groups. Most research has been conducted among adults; very few studies have focused on children, more on adolescents and young adults, and few again on SGM older adults.[12]

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[12] Fredriksen-Goldsen KI, et al. The Health Equity Promotion Model: Reconceptualization of Lesbian, Gay, Bisexual, and Transgender (LGBT) Health Disparities. American Journal of Orthopsychiatry: November 2014, Vol. 84, No. 6, pp.653-663.

NIH Sexual and Gender Minority Research Coordinating Committee

In 2009, the NIH commissioned the Institute of Medicine (IOM) to conduct the first-ever comprehensive study on the state of the science on the health status of lesbian, gay, bisexual, and transgender (LGBT) populations, resulting in the landmark 2011 publication, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.[13] The report summarized what was known about the specific health and wellness issues of LGBT populations as a group, and made recommendations for improving our understanding of these populations. One of the major conclusions of the IOM report was that far too little is known about the health needs of lesbians, gays, bisexuals, or transgender persons in the United States, and the report issued a call to researchers and the NIH, in particular, to support and conduct additional research.

In response, the NIH formed the NIH Lesbian, Gay, Bisexual, and Transgender (LGBT) Research Coordinating Committee (RCC) in May 2011, and that, as of January 2015, was renamed the Sexual and Gender Minority Research Coordinating Committee. This committee is charged with "developing and coordinating possible research and training opportunities to be undertaken at NIH as a result of recommendations from the IOM report on LGBT health issues." The RCC conducted an analysis of the ongoing NIH research portfolio in LGBT health as a starting point for considering the IOM recommendations. By "mapping" the portfolio to the IOM recommendations, the RCC identified gaps and opportunities in the research areas supported by the NIH. In addition, the RCC examined the NIH research portfolio in the context of demographic variables such as age, race, ethnicity, and the specific LGBT populations involved.

The RCC's initial report was released in January 2012.[14] Based on results of the FY 2010 LGBT portfolio analysis, the RCC identified several areas of opportunity, which parallel recommendations from the IOM report:

- Expanding the scientific knowledge base of LGBT health
- Improving methodologies to reach these populations
- Training and career development in LGBT health research, and enhancing cultural competency of physicians and researchers
- Facilitating communication between NIH and the LGBT research community
- Facilitating trans-NIH collaboration and coordination in this research area

After analyzing the NIH research portfolio on LGBT health, the RCC identified a number of opportunities for advancing research in this area. In addition, valuable opportunities were noted for collaborating with other components of the U.S. Department of Health and Human Services (DHHS) to address critical health-related issues. The RCC concluded that "Going

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[13] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. The National Academies Press, 2011.

[14] *Consideration of the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals.* NIH LGBT Research Coordinating Committee. January 2012.

forward, it may be helpful for the NIH to establish a trans-NIH mechanism in order to develop an integrated approach for pursuing these opportunities as well as monitoring progress in this important area of public health.”

Development of the SGM Strategic Plan

Following the release of the FY2010 LGBT Portfolio Analysis, the RCC began to develop a Strategic Plan for SGM Health Research. The group gathered data for the plan from several key sources:[15]

- A **review of the scientific literature** spanning the LGBT population conducted in the 2011 IOM report
- An **analysis of the NIH SGM research portfolio** covering fiscal year (FY) 2012 (conducted similarly to the FY2010 analysis, see Appendix B)
- Multiple **listening sessions** with diverse audiences, including SGM health researchers and advocates
- A **Request for Information** (RFI) through which members of the public could share their thoughts, experiences, and recommendations

Once the data were collected, NIH staff reviewed, analyzed, collated, and assembled all responses, and found that certain specific themes emerged. In particular, a majority of responses incorporated some aspect(s) of one or more of the following:

- **Expand the knowledge base** of SGM health and well-being through NIH-supported research
- **Remove barriers** to planning, conducting, and reporting NIH-supported research about SGM health and well-being
- **Strengthen the community** of researchers and scholars who conduct research relevant to SGM health and well-being
- **Evaluate progress** on advancing SGM research

From these data, NIH distilled the following research and research-related goals and objectives. The NIH SGM RCC believes that these goals and objectives will provide the building blocks for future discovery, and lead to the development of additional priority goals and objectives in future years to improve the health of SGM populations.

Goal 1: Expand the Knowledge Base of SGM Health and Well-being Through NIH-Supported Research

Both peer-reviewed research and NIH's information-gathering efforts (e.g., RFI, listening sessions) have highlighted research needs that are specific to SGM populations. One example is the need to collect basic demographic research on SGM populations, individually and as a whole; numerous respondents called for the collection of epidemiologic, demographic, or other foundational data that will inform intervention research.

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[15] Detailed descriptions of the results in each of these areas can be found in Appendices A-C.

Another example is the need to better understand the health effects of exogenous hormone use among transgender persons and individuals with DSD/intersex conditions. The use of such hormones, including off-label use and use outside the clinical context, is widespread, but a dearth of reliable data leaves patients and clinicians with concerns about dosage, drug interactions, long-term implications for cognition, risk factors for disease (e.g., cardiovascular disease, cancer), and other negative health outcomes.

NIH also received input reflecting the need for research in many areas in which the NIH is already active, including the presumed differential effects of depression and other mental illnesses; the influence and effects of stigma on physical and mental health and behavior; smoking and tobacco use; and health and well-being across the life course, from early childhood to old age. NIH supports robust research portfolios in each of these areas, some of which focus on or include SGM populations. Therefore, it is reasonable to anticipate that the portfolio can be built upon by incorporating additional SGM-relevant research questions into novel and existing studies in these areas to generate new and needed information.

Several methodological difficulties, including small sample sizes and difficulty identifying members of SGM populations, may contribute to the lack of scientific information about SGM populations. Individuals that self-identify as SGM make up a small proportion of the United States population – the National Health Interview Survey (NHIS) estimates that less than three percent of Americans self-identify as gay, lesbian, or bisexual.[16] SGM individuals may be reluctant, for a variety of reasons, to self-identify as such to a clinician or researcher. Further, with a small population that is divided up into subpopulations by sexual orientation, gender identity, race and ethnicity, age and other factors, it is challenging to collect sufficient data that will pass statistical tests of validity. Such validity is essential, ultimately, for informing clinical decisions and care.

Objective 1: Encourage extramural and intramural investigators to conduct SGM research in priority areas, including those identified in the IOM report and in NIH portfolio analyses.

These areas include, but are not limited to:

- **Transgender health**
- **DSD populations[17]**
- **Longitudinal studies of chronic illness**
- **Varying perspectives: minority stress, life course, intersectionality,[18] social ecology**

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[16] http://www.cdc.gov/nchs/data/nhsr/nhsr077.pdf

[17] The experts who prepared the IOM report considered "intersexuality" to be beyond the scope of their study. In the report, they noted certain "overlapping" issues with LGBT health, acknowledged that "very little research exists," and stated that intersexuality is "a separate research topic with critical issues." While recognizing the distinctive health research issues presented by DSD/intersex conditions, NIH includes them with other understudied SGM populations, so as to draw attention to research needs for the conditions.

- **Across SGM populations: demographic and descriptive information, family and interpersonal relations, health services, mental health, and physical health**

Priority research encompasses studies involving small or emerging SGM populations, or subpopulations about which limited data exist – e.g., Native American Two-Spirit or “gender-variant” populations. Below are some of the sub-areas of interest:

- Violence against SGM populations
- Behavioral and social science topics
- Romantic/sexual partners/spouses of SGM individuals, particularly regarding disease treatment and/or family-planning issues
- Transgender health research
    - Gender identity
    - Gender transition and exogenous hormone use
- DSD populations
    - Improving early diagnosis of DSD
    - Genitosurgery/gender assignment decisions, timing, and outcomes
    - Psychosocial and functional impacts of DSD on childhood and adolescent development
    - Improving clinical management of DSD over the life course

Aligns with IOM LGBT Report Recommendation #1[19]

Objective 2: Promote the development and implementation of appropriate measures, methods, and resources to facilitate research relevant to SGM populations.

This objective includes efforts to support the development of consistent terminology and common research data elements that would advance research in the priority areas described above, and aligns with the IOM Report recommendation (“NIH should support the development and standardization of sexual orientation and gender identity measures”). In addition, NIH will promote the development of methods and measures appropriate for data collection in populations that are small or “easy-to-miss.” Existing collaborations with federal partners, such as the Centers for Disease Control’s (CDC) National Center for Health Statistics (NCHS) on the NHIS, National Survey of Family Growth (NSFG), and the National Health and Nutrition Examination Survey (NHANES), will be explored for options to facilitate data collection of sexual orientation and gender identity (SOGI) information.

Aligns with IOM LGBT Report Recommendations #2-5

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[18] Encompasses a set of foundational claims and organizing principles for understanding social inequality and its relationship to individuals’ marginalized status based on such dimensions as race, ethnicity, and social class

[19] Institute of Medicine. *Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. The National Academies Press, 2011.

Objective 3: Encourage researchers to incorporate SGM-relevant scientific questions into extramural and intramural projects, programs, and initiatives.

NIH supports research in a wide range of scientific disciplines, and will encourage the incorporation of SGM-relevant research questions into these efforts, where appropriate and feasible. Listening session participants and RFI respondents cited an array of research areas of interest, which include, but are not limited to:

- Cancer risk
- Cardiovascular disorders
- Depression, suicidality, and other mental health conditions
- Endocrine problems
- Exogenous hormone use and risk
- Exposure to violence
- HIV (and other sexually transmitted infections [STI]) risk and pathogenesis
- Impact and effects of stigma (minority stress)
- Needs across the lifespan, including needs for aging SGM individuals
- Obesity
- Racial, ethnic, sex and gender differences
- Resiliency or protective factors affecting health outcomes
- Risk for infectious diseases (e.g., hepatitis C)
- Tobacco and alcohol/drug use

All of these are current areas of interest at NIH and within the agency's constituent Institutes, Centers, and Offices (ICOs), and NIH will work to expand the scope of work to integrate SGM populations, as appropriate and consistent with each ICO's mission and priorities.

For example, NIH plans to launch an SGM Health Research Supplement Program, which is scheduled to begin in FY2016. This effort is designed to encourage existing NIH-funded projects to expand their focus to include specific research questions related to SGM populations.

Aligns with IOM LGBT Report Recommendation #1

Goal 2: Remove Barriers to Planning, Conducting, and Reporting NIH-Supported Research about SGM Health and Well-being

In addition to addressing priority areas of research in SGM health, the NIH also must ensure that barriers to advancing SGM health research also are addressed. Better coordination of activities related to SGM health research within and throughout the NIH ICOs would further highlight NIH's commitment to this area of research and facilitate its growth. Enabling applicants to understand the characteristics of successful applications and ensuring NIH review expertise in SGM health research can fully allow innovative and progressive work in the field to continue and expand as science calls for it. In addition, NIH can work to ensure that its staff, including intramural researchers:

- Are aware of SGM-related research issues
- Have resources available to answer their questions
- Have a dedicated resource to which they can refer investigators interested in learning more about opportunities for SGM researchers and researchers interested in SGM-relevant topics

Objective 1: Establish an NIH Sexual and Gender Minority Research office to coordinate and integrate SGM research activities across NIH, collaborate with other Federal agencies, and develop and implement a comprehensive outreach plan to engage SGM health researchers, experts, advocates, and the general public.

This is envisioned to be a trans-NIH office within the NIH Office of the Director, similar in function to other trans-NIH coordinating offices, such as the NIH Office of Research on Women's Health and the Office of Behavioral and Social Sciences Research. The office would facilitate enhanced coordination of NIH-funded SGM health research efforts and provide guidance to NIH staff, the extramural community, and health research advocates regarding SGM health research at NIH.

The office will support the RCC and work with the Committee to optimize areas of existing coordination and collaboration within NIH and with other federal agencies, and identify options for acting on opportunity areas for collaborative work and outreach (including stakeholder engagement and web-based outreach).

Facilitates IOM LGBT Report Recommendation #1

Objective 2: Develop and implement activities to provide extramural and intramural researchers interested in SGM-relevant research topics with the skill set necessary to compete successfully for NIH funding.

The NIH funding process is one that rewards scientifically meritorious applications that look to advance the understanding of living systems and improve the health of the Nation. For many potential applicants of NIH support, this system can seem daunting and difficult to navigate. NIH offers many resources to aid applicants in increasing their understanding and subsequent success in the grant application process. For researchers in a field that is fairly underdeveloped, as in the case of SGM health research, that challenge may loom especially large. The goal here is to integrate existing applicant education and outreach with activities that can address questions and issues specific to applicants interested in SGM health research. This would include clarifying information on current policies and facilitating mentorship opportunities for early-career SGM researchers.

Facilitates IOM LGBT Report Recommendation #1, aligns with Recommendation #6

Objective 3: Increase expertise in sexual and gender minority health research within and across existing NIH review panels and study sections, as needed.

Review expertise and service is essential to the NIH grants process, both for the agency and for researchers. Extramural peer reviewers provide NIH with excellent essential expertise and insight into different areas of research, and peer review service gives reviewers invaluable insight into the NIH grants process and the characteristics of successful applications. Assuring expertise in SGM health research in NIH review panels and study sections, where applicable, will ensure both appropriate reviews of SGM health-related applications, and increase exposure to the NIH grants process for SGM health researchers. The current Early Career Review program, run by the NIH Center for Scientific Review (CSR), provides an example of how expertise can be expanded, while offering reviewers important exposure to grant review.

Facilitates IOM LGBT Report Recommendation #1, aligns with Recommendation #6

Objective 4: Encourage cultural competency[20] training opportunities on the specific characteristics of SGM-specific research to NIH-funded extramural and intramural clinical research trainees and researchers.

Clinical, epidemiological, behavioral and other types of related research will play an integral role in the advancement of SGM health research. To facilitate the successful conduct of this research, SGM-specific awareness, considerations, and needs should be accommodated in the research design and implementation. People who identify as SGM will be more likely to participate in and support clinical research that is cognizant and respectful of their needs. Those who conduct research in this area will need access to resources and tools that can aid in developing awareness, and in adapting their research to meet SGM-specific needs, as appropriate (often referred to as cultural competency). Resources to help facilitate understanding should be crafted for and made available to researchers and research trainees in both the NIH-funded extramural and intramural research programs.

Facilitates IOM LGBT Report Recommendations #6-7

Goal 3: Strengthen the Community of Researchers and Scholars Who Conduct Research Relevant to SGM Health and Well-being

Strengthening the community of researchers and scholars who conduct research relevant to SGM health and well-being has emerged as a high NIH priority. Networking, collaboration, and information-sharing among investigators will speed the pace of SGM research, and the NIH can

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[20] Sexual and gender minority (SGM) cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work when interacting with members of the SGM community. Because a variety of factors can influence health communication, including behaviors, communication styles, customs, beliefs, perspectives, and risk factors, cultural competence is critical for achieving accuracy in clinical research. Poor planning in clinical research – planning that does not take into account principles of cultural competence – may yield inaccurate results. For the provider of health information or health care to SGM individuals, these elements influence beliefs and belief systems surrounding health, healing, wellness, illness, disease, and delivery of health services, while recognizing the unique attributes and challenges facing this population. SGM culturally competent care is defined as care that respects diversity in the patient population and cultural factors that can affect health and health care. Cultural competence is widely seen as a foundational pillar for reducing disparities through culturally sensitive and unbiased quality care that is respectful of and responsive to the needs of the diverse pool of patients within the community. The National Institutes of Health (NIH) recognizes the challenge presented by the complex health care needs of the SGM community and highlights the interconnectedness of and need for basic and clinical research and respectful, quality care in this burgeoning area. – Modified from the DHHS Office of Minority Health and National Institutes of Health definitions of cultural competency.

play a key role in bringing this community together. In addition, bolstering the SGM research community will ensure that NIH is well-poised to support high-quality and innovative work in SGM health research, with a pool of research experts upon whom it can call for insight and perspectives specific to the field.

In addition to the objectives listed below, the NIH will consider developing state of the science conferences around specific SGM-related topics, and enhance its presence and visibility at SGM conferences and special interest groups of large conferences.

Objective 1: Establish an NIH SGM Health Research Working Group of the NIH Council of Councils, to provide subject matter expertise and strategic perspective for extramural and intramural NIH-funded SGM health research and related efforts.

This working group will advise the Council of Councils on strategies for the NIH to engage with external stakeholders on issues specific to SGM health research, and to aid the agency in navigating the landscape of SGM health issues as it evolves. The working group also will serve as a resource in the development of future NIH SGM Health Research Strategic Plans. Nominations will be solicited by Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) for SGM health research experts. Members of the working group will be selected by the DPCPSI Director who will seek input from the SGM research office and the RCC.

Facilitates IOM LGBT Report Recommendation #1

Objective 2: Provide resources for training on and about SGM-relevant research considerations as part of the professional training opportunities and tools for extramural and intramural NIH staff.

NIH staff at all levels across the agency play substantive roles in advancing research; they can benefit from information and resources on SGM health research, especially as they interact with fellow researchers, applicants, program directors, grantees, and the general public. Providing opportunities for NIH staff to receive continuing education on SGM-relevant research and related issues will therefore not only benefit grantees and potential grantees (by creating a culturally competent NIH workforce), but will also benefit NIH staff (by giving them access to appropriate tools and strategies to understand and address the unique needs of these populations).

Facilitates IOM LGBT Report Recommendation #1

Goal 4: Evaluate Progress on Advancing SGM Research

Objective 1: Monitor and evaluate progress in advancing SGM health research using both qualitative and quantitative methods.

NIH will evaluate its efforts on an annual basis to ensure that NIH remains on track and meets milestones. On a biennial basis, the RCC will prepare and disseminate a report on standard NIH tracking variables as they relate to SGM research applications, such as number of applications, success rates, etc. The biennial reports also will include an analysis report on the NIH SGM research portfolio. During the implementation of this Strategic Plan, NIH will develop an evaluation plan, and call upon experts to review the state of the science and our progress toward meeting the outlined goals and objectives. Existing internal tracking tools will be updated in order to ensure that SGM tracking reports are accurate and complete, and to ensure that reporting is transparent and timely. Finally, NIH will involve all of its ICOs through the SGM research office and the SGM RCC's coordination of the evaluation activities as a means to increase agency buy-in and ensure that the evaluations are complete and comprehensive.

Facilitates IOM LGBT Report Recommendation #1

Objective 2: In 2018, convene a panel of SGM health research experts to review NIH's mid-course progress on the Strategic Plan.

NIH will also evaluate its efforts on meeting the goals and objectives of the SGM Health Research Strategic Plan. This will allow for mid-course correction in the implementation of the Strategic Plan, as well as provide valuable input on the next iteration of the Plan. In bringing together experts in SGM health and health research, this will ensure another level of engagement with stakeholders in both the evaluation of progress and the evolution of NIH's efforts to advance SGM health research.

Appendices

- **Appendix A**: National Institutes of Health FY 2012 Sexual and Gender Minority Health Research Portfolio Analysis Report
- **Appendix B**: Data Synthesis Exercise from Input Gathered on SGM Health Research Needs and Priorities
- **Appendix C**: NIH Request for Information: The Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations
- **Appendix D**: Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations
- **Appendix E**: NIH Sexual and Gender Minority Research Coordinating Committee Roster

Appendix A

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

Appendix A

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Appendix A

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.

Appendix A

[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.]

Appendix A

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)

Appendix A

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.

Appendix A

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.

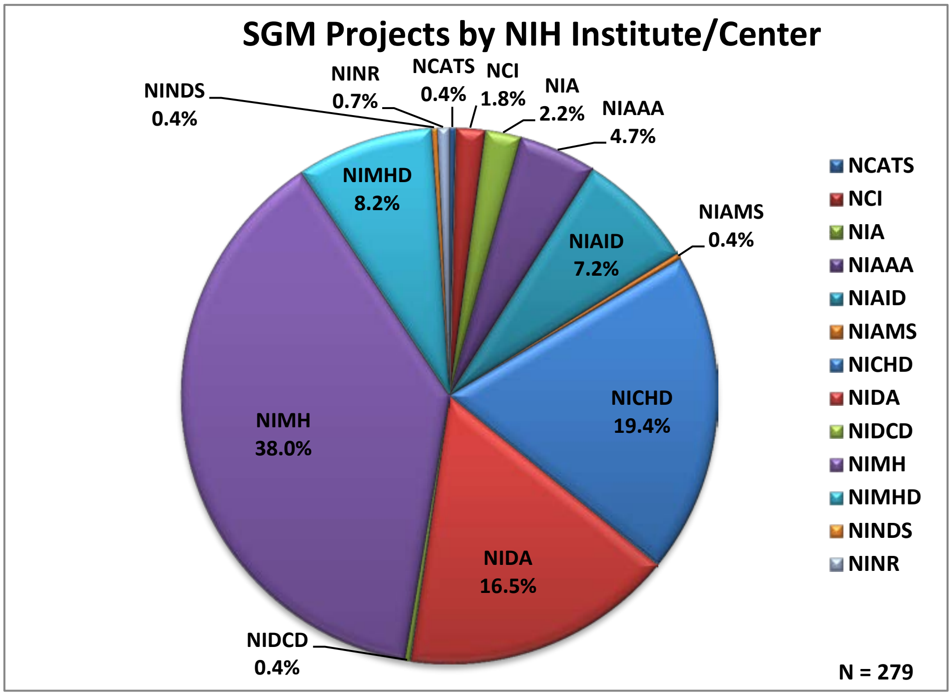

Figure 1. SGM Projects by NIH Institute or Center. *Thirteen NIH ICs support SGM projects, with the largest contribution from NIAID, NICHD, NIDA, NIMH, and NIMHD.*

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*.

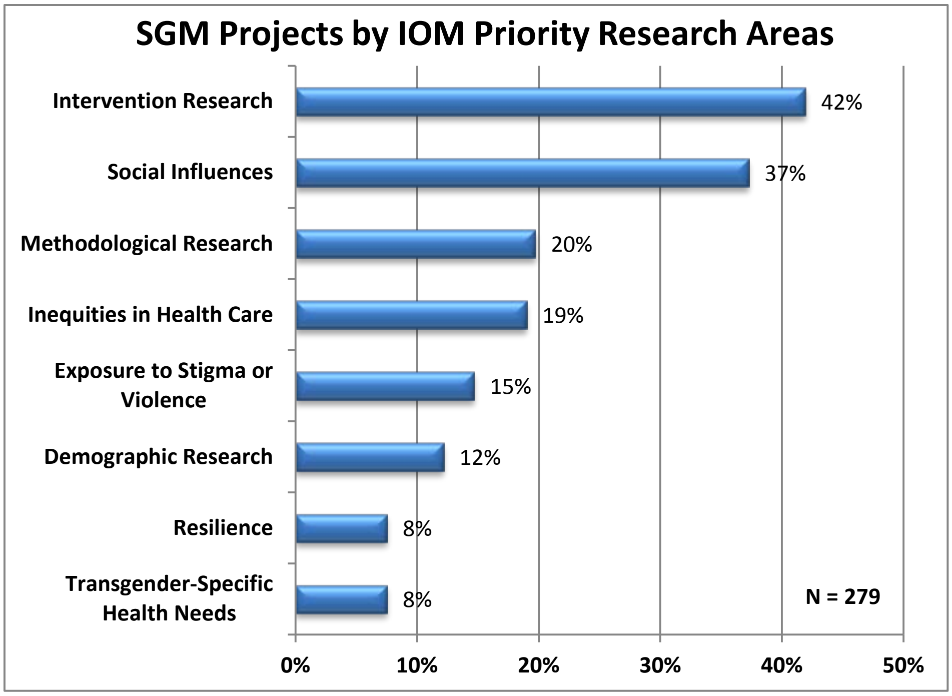

Figure 2. SGM Projects by IOM Priority Research Areas. *Intervention Research and research addressing Social Influences were the IOM priority areas most frequently addressed in NIH-supported SGM projects.*

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

Appendix A

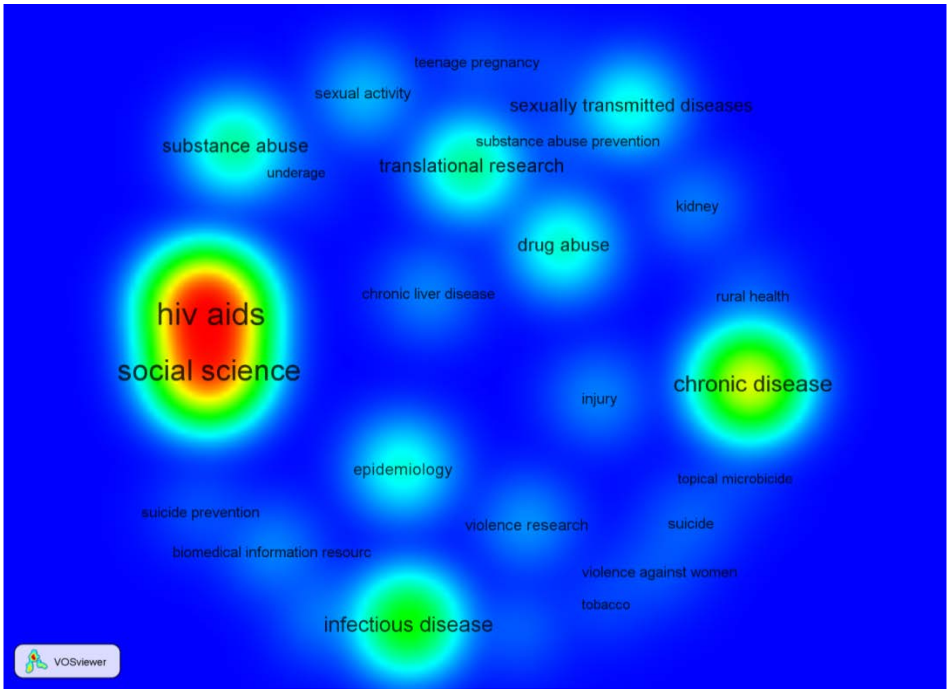

Figure 3. Map of RCDC Categories for SGM Projects. *HIV/AIDS projects, which constitute the largest cluster, are closely linked with Social Science projects; virtually all Prevention projects are focused on HIV/AIDS.*

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.

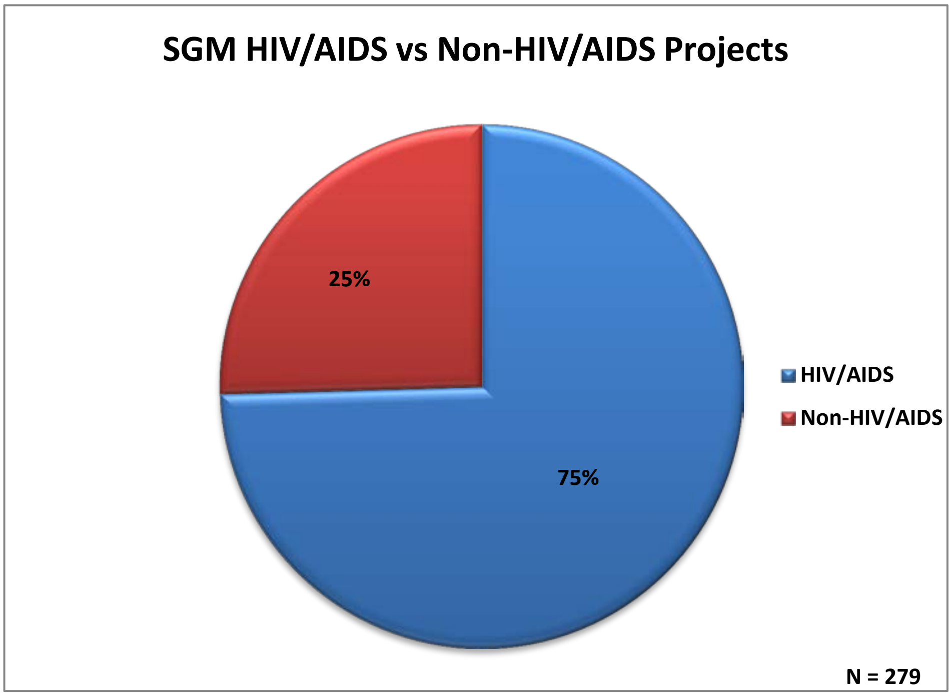

Figure 4. SGM HIV/AIDS vs. Non-HIV/AIDS Projects. *The majority of SGM projects are focused on HIV/AIDS.*

Appendix A

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.

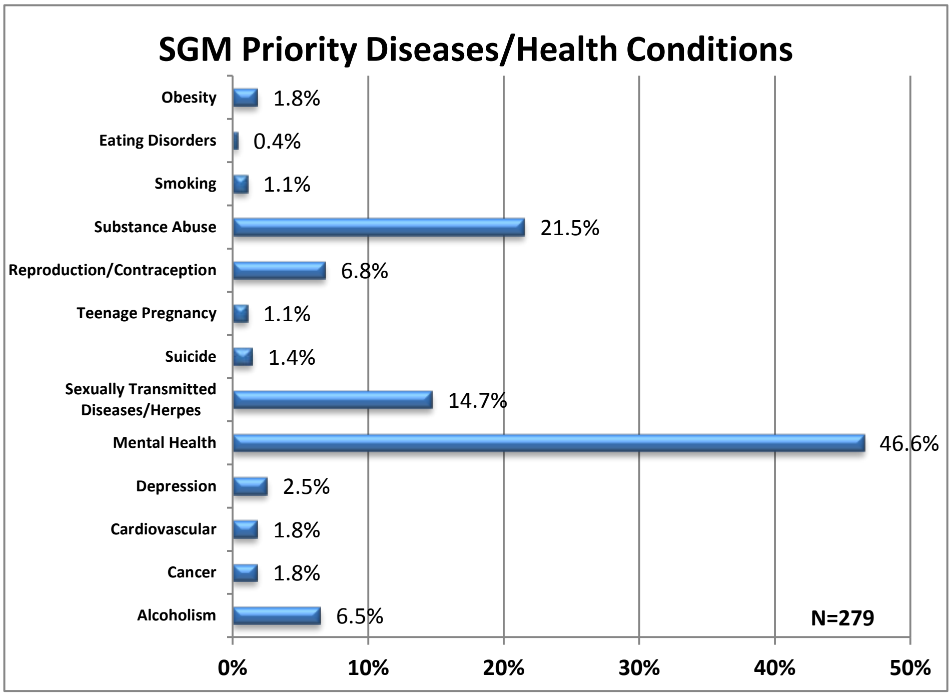

Figure 5. SGM Priority Diseases/Health Conditions. *Of those grants not concentrated on HIV/AIDS research (25% of the portfolio), Mental Health, Substance Abuse, and Sexually Transmitted Diseases/Herpes represent the most projects focused on SGM-relevant diseases/health conditions.*

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.

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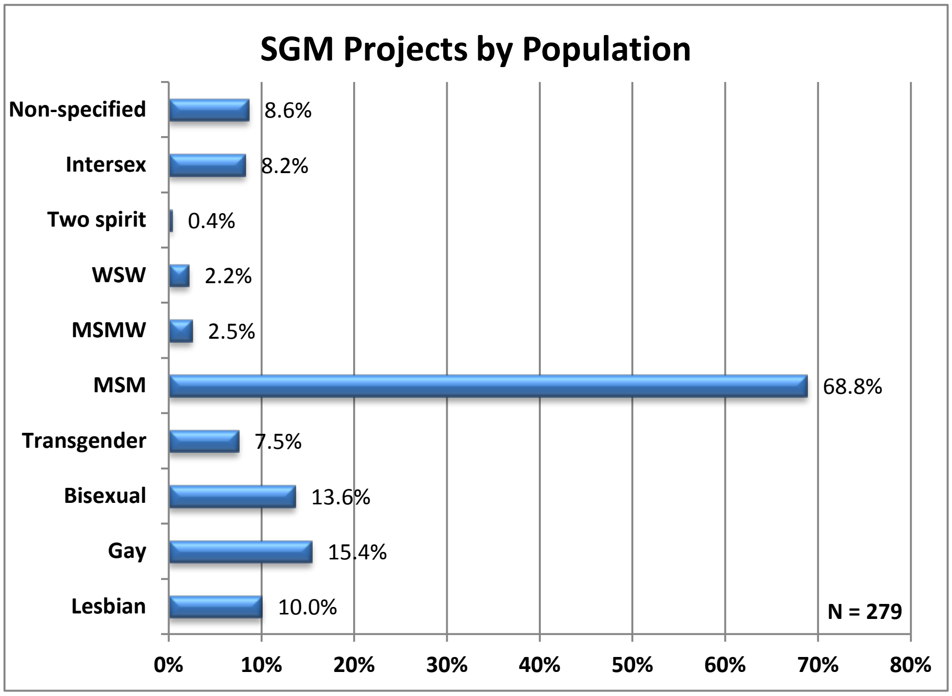

Figure 6. SGM Projects by Population. *Men who have Sex with Men (MSM) are the most commonly represented population.*

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

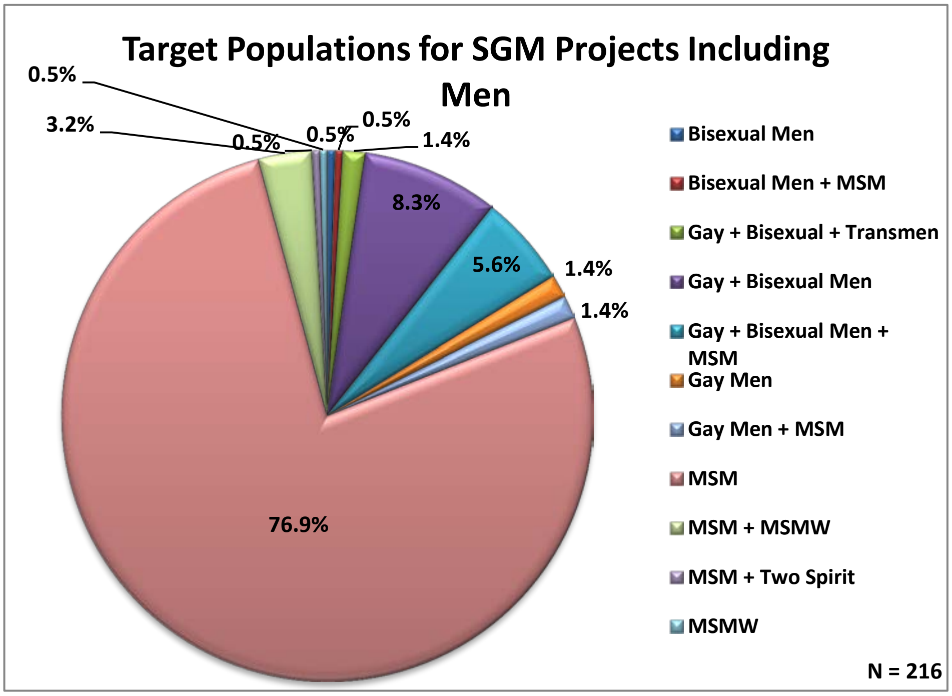

Figure 7. Target Populations for SGM Projects Including Men. *The vast majority of SGM projects that included men identified only MSM as the target population.*

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.

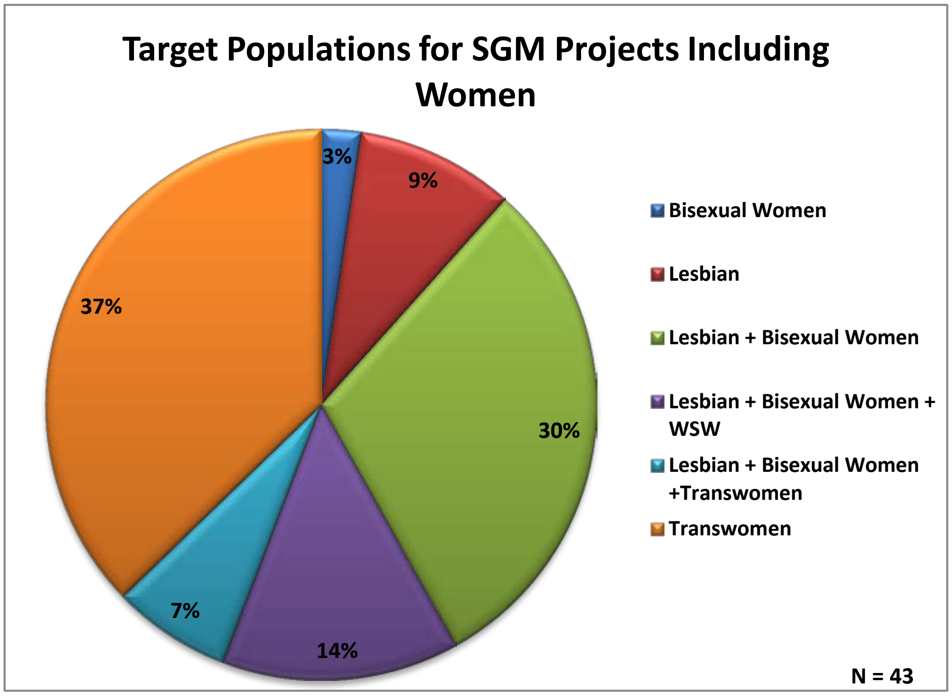

Figure 8. Target Populations for SGM Projects Including Women. *SGM projects that include women primarily focus on transgender male-to-female individuals (transwomen), either alone or in combination with lesbians and bisexual women.*

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.

Appendix A

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.

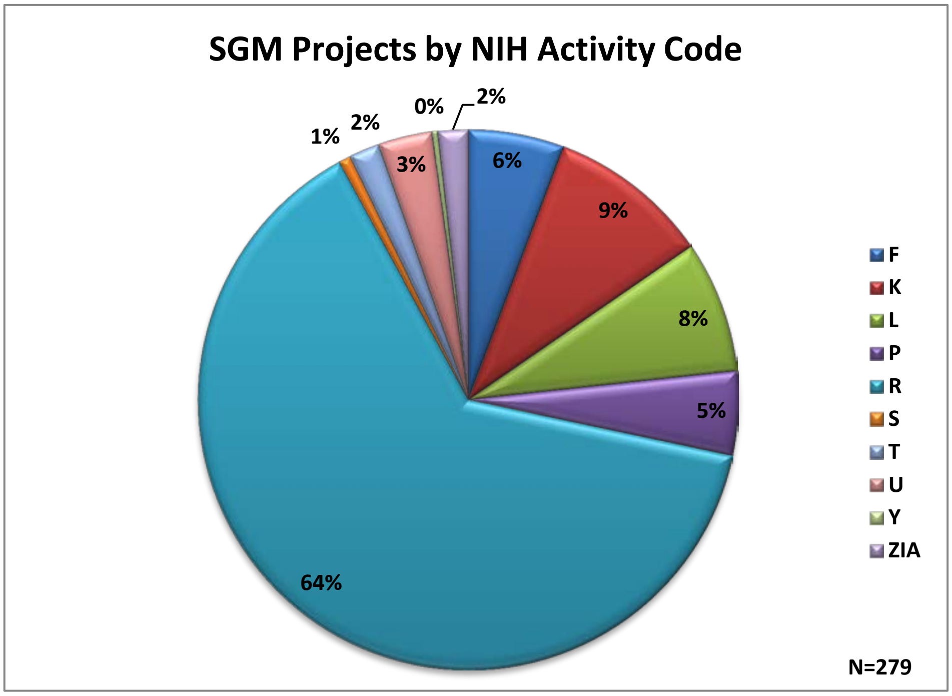

Figure 9. SGM Projects by NIH Activity Code. *Research project grants (R activities) comprise the largest proportion of SGM projects.*

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.

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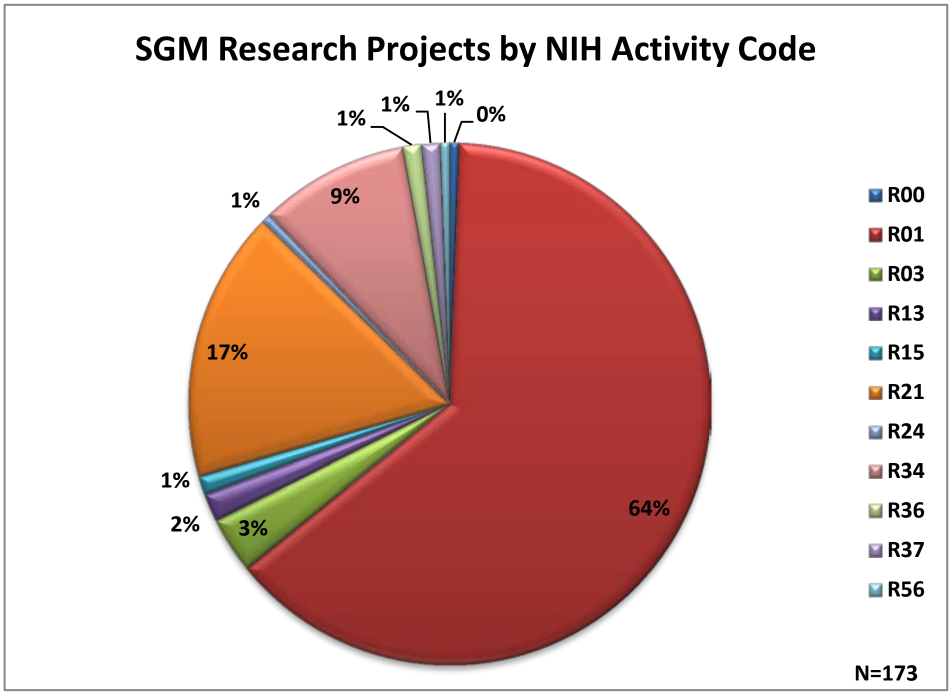

Figure 10. SGM Research Projects by NIH Activity Code. *R01 grants are the largest category of research projects.*

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%).

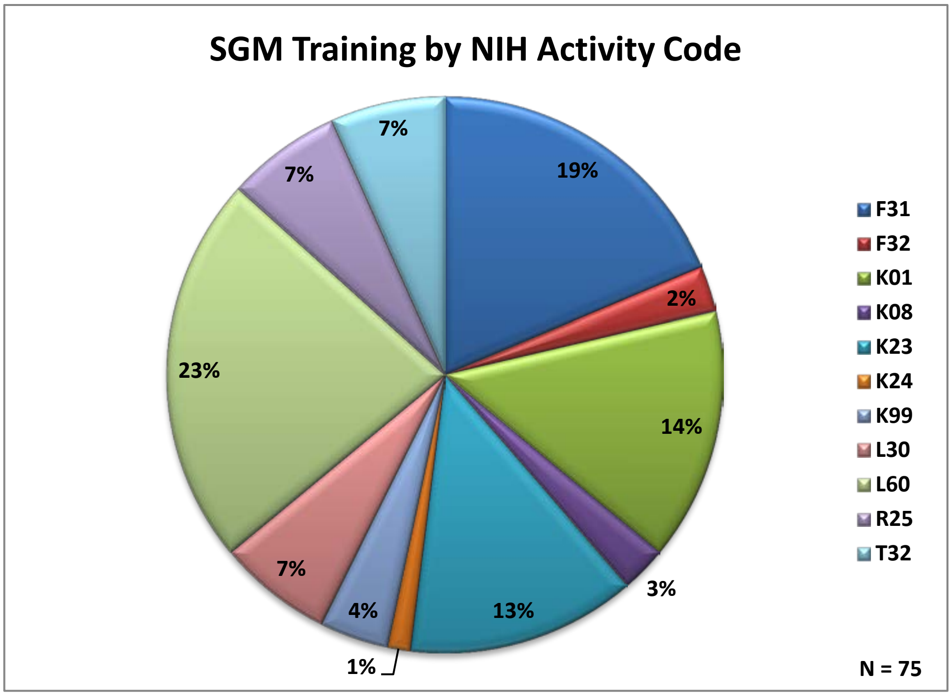

Figure 11. SGM Training by NIH Activity Code. *A range of activities is used to support training programs on SGM topics, with the largest proportion funded through the Loan Repayment Program for Health Disparities Research (L60).*

Appendix A

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.

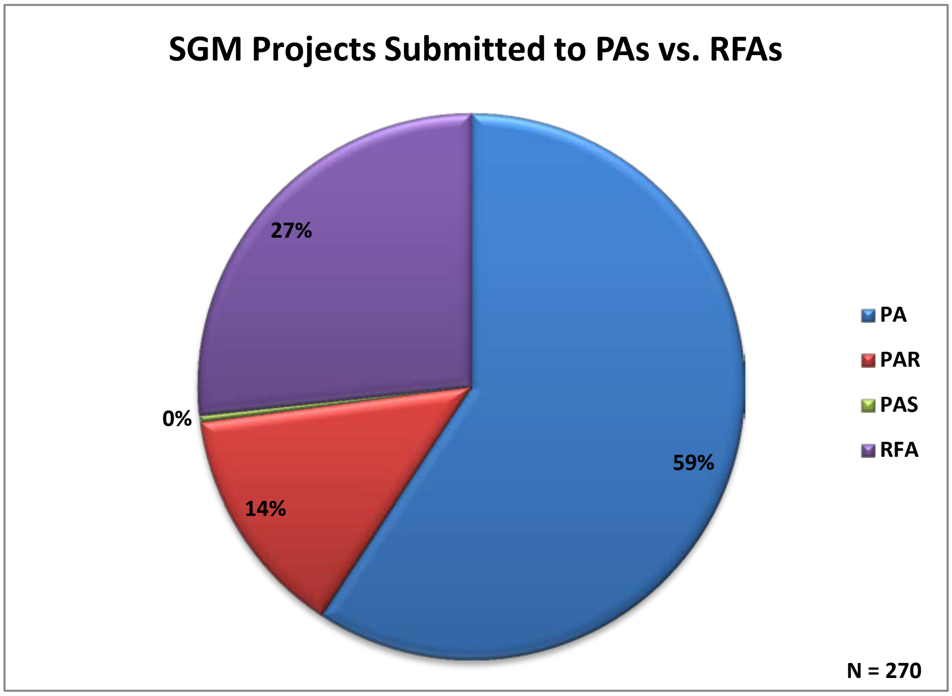

Figure 12. SGM Projects Submitted to PAs vs. RFAs. *The majority of funded SGM projects were submitted to a PA.*

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).

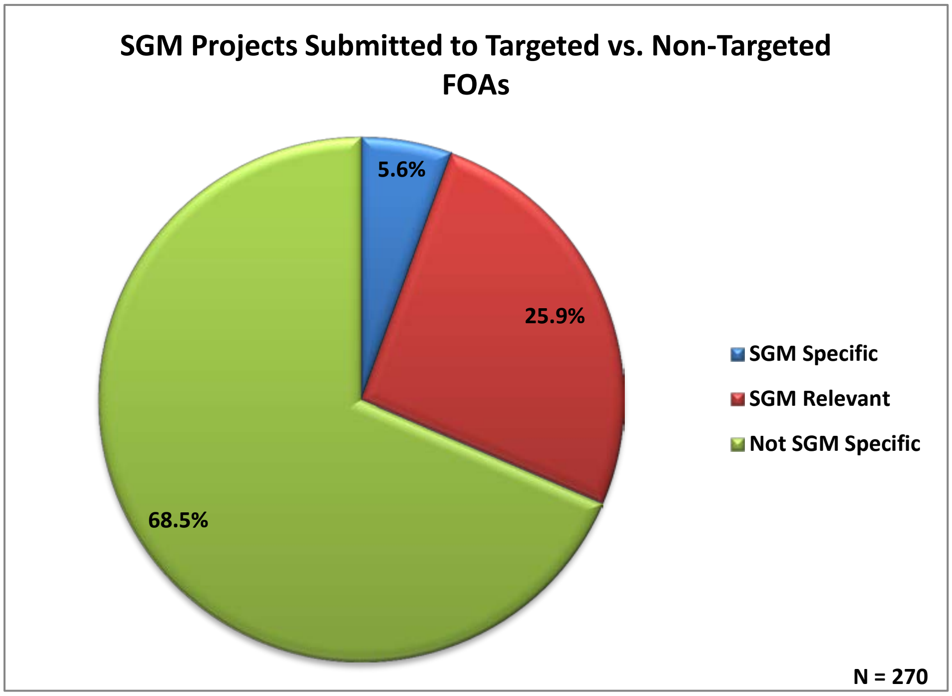

Figure 13. SGM Projects Submitted to Targeted vs. Non-Targeted FOAs. *The majority of funded SGM projects were submitted to Not SGM-Specific FOAs.*

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 A

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%).

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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

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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

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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 A

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

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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

Appendix B

Data Synthesis Exercise from Input Gathered on SGM Health Research Needs and Priorities

10 September 2014

NIH LGBTI Research Coordinating Committee

Contents

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Section I. Introduction

NIH has supported or sponsored multiple activities to identify research, research training, and research communication needs relevant to the health of persons from sexual and gender minorities. The current report summarizes and synthesizes the data from these multiple activities. Many voices were raised and many thoughts were shared throughout the planning activities; one purpose of the data summary and synthesis is to preserve and make available for further study the comments and contributions of the many people who participated. Another purpose of the current report is to standardize the reporting and analysis of the data received from multiple sources and under various conditions. Most of the data were qualitative, and rigorous, recognized methods of qualitative data analyses were employed. The current report summarizes and synthesizes data from other, existing reports, most of which are available through an NIH website. Much detailed information and analysis is contained in the original reports.

All of these activities have occurred within the context of the NIH mission and goals, which are stated in Section A following. Moreover, a frame for the planning activities was articulated early on and made publicly available in the NIH Request for Information, presented in Section B following. Finally, NIH commissioned a report from the Institute of Medicine that has been highly influential at NIH and in the community or researchers, advocates, and other stakeholders, and the recommendations from the NIH report are presented in Section C following. Together, Sections A, B, and C motivated and informed all the planning efforts. The starting point for the data synthesis exercise comes from the NIH mission and goals, the NIH SGM framework, and the IOM recommendations.

Since 2012, most of these activities were coordinated by the NIH LGBTI Research Coordinating Committee (LGBTI RCC). A primary goal of the RCC is to develop and implement a strategic plan. Section II of the current report is the synthesis of all the data collected and all the reports reviewed, which means that it is also a synthesis of Sections III through VI and can serve as the basis for the strategic plan. Section III contains excerpts from an internal NIH analysis and response to the IOM report. Section IV includes excerpts from the NIH LGBTI FY 2012 portfolio analysis. Section V includes a summary of planning outcomes about DSD research produced by NICHD. Section VI. Summarizes and synthesizes seven separate NIH LGBTI RCC outreach activities. The outreach activities themselves are described in Table 1. Information about the analysis is contained in Table 2. Then there is a standard presentation for each activity: description of the prompts or discussion starting points, a narrative summary (not available for all activities), and then a tabular summary. The tabular summary relates the raw data to coded categories and the observed goals and objectives.

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Section A. Statement of the mission and goals of NIH

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

The goals of NIH agency are

- to foster fundamental creative discoveries, innovative research strategies, and their applications as a basis for ultimately protecting and improving health;
- to develop, maintain, and renew scientific human and physical resources that will ensure the Nation's capability to prevent disease;
- to expand the knowledge base in medical and associated sciences in order to enhance the Nation's economic well-being and ensure a continued high return on the public investment in research; and
- to exemplify and promote the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science.

NIH's major activities are
  - Fund, support, and conduct extramural and intramural research
  - Provide career development and training for researchers
  - Communicate research results

Section B. SGM topics introduced in the NIH RFI

- Methodological or other challenges to data collection and analysis for small and/or heterogeneous LGBTI populations…
- Opportunities to expand the knowledge base of LGBTI health…existing data collection efforts, and other resources and scientific advances on which further research could be built
- Training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency
- Effective ways to engage with the LGBTI health research and advocacy communities, which include the broad range of populations that may be encompassed by the term LGBTI
- Effective ways to enhance communication between the NIH and the LGBTI research community to enhance practical understanding of the NIH mission, as well as the NIH funding and review processes, and encourage individuals engaged in research and/or training in LGBTI health to compete for funding through various NIH mechanisms

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- Outcome Indicators…Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully

<u>Section C. Summary of IOM Report Recommendations</u>

Note: The following statements are excerpted from the IOM (2011) Report, pages 6-10.

1. The NIH should implement a research agenda designed to advance knowledge and understanding of LGBT health.
    - LGBT research should consider the following cross-cutting perspectives:
        - Minority stress;
        - Life course;
        - Intersectional (racial, ethnic, socioeconomic and geographic diversity); and
        - Social ecological perspective.
    - Essential research areas are:
        - Demographic research;
        - Social influences on the lives of LGBT people;
        - Inequities in health care;
        - Intervention research to develop and test the effectiveness of interventions to address health inequities and negative health outcomes experienced by LGBT people
        - Transgender-specific health needs, e.g., the health implications of hormone use.
2. Data on sexual orientation and gender identity should be collected in federally funded surveys administered by the Department of Health and Human Services (HHS) and in other relevant federally funded surveys.
3. Data on sexual orientation and gender identity should be collected in electronic health records.
4. NIH should support the development and standardization and gender identity measures.
5. NIH should support methodological research that relates to LGBT health.
6. A comprehensive research training approach should be created to strengthen LGBT health research at NIH. This recommendation included expanding NIH intramural and extramural training programs…focusing on three audiences: researchers who are working with or considering working with LGBT populations, researchers who may not be aware of LGBT health issues, and NIH staff.
7. NIH should encourage grant applicants to address explicitly the inclusion or exclusion of sexual and gender minorities in other samples.

Note: See also Table 7.1, Research Opportunities for Studying Lesbian, Gay, Bisexual, and Transgender Health Across the Life Course (pp 300-301).

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Section II. Overall Synthesis: Observed Goals and Objectives

Goal 1: **Expand the knowledge base** of SGM health and well-being through NIH-supported research

- Objective: Develop a research agenda that supports the research opportunities identified in the IOM Report
    - Perspectives: Minority Stress, Life Course, Intersectionality, Social Ecology
    - Cross SGM populations: demographic and descriptive information, family and interpersonal relations, health services, mental health, and physical health
- Objective: Further develop, prioritize, and fund the research priorities already identified for specific SGM populations
    - DSD populations
        - Improving Diagnosis of DSDs
        - Genitosurgery/Gender Assignment Outcomes
        - Psychosocial and Functional Impacts on Development with DSD
        - Improving Clinical Management of DSD
    - Transgender health research
        - Gender transition and hormone use
        - Gender identity
        - Violence against transgender people
        - Behavioral and social science topics
    - Longitudinal studies of chronic illness

- Objective: Establish SGM as a trans-NIH priority (Get IC support)
    - Identify SGM research opportunities consistent with the missions of specific ICs
    - Identify areas for trans-NIH collaborations
    - Secure Common Fund or other support

- Objective: Generate knowledge on terminology and common data elements that would advance research
  AKA: Support the implementation of the following IOM Report recommendation: "NIH should support the development and standardization of sexual orientation and gender identity measures" (p. 9)

- Objective: Identify and prioritize specific health research topics for collection of epidemiologic and demographic data (or other foundational data for interventional research)

- Objective: Facilitate dissemination of emerging SGM research data to stimulate development of fields of study

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- Objective: Explore patient registries as a means of increasing the population of SGM persons available for research studies

- Objective: Explore data sharing

- Objective: Integrate SGM research aims into existing programs and projects

Goal 2: **Remove barriers** to planning, conducting, and reporting NIH-supported research about SGM health and well-being

- Objective: Coordinate SGM activities throughout NIH
  - Create a trans-NIH Office on SGM Health Research and Health Research Training
  - Maintain the RCC
  - Identify IC Contacts and ensure their knowledge of SGM health research topics
  - Develop a stronger SGM presence on NIH websites

- Objective: Facilitate review of SGM research and training proposals
  - Contribute to knowledge of SROs about of SGM health research topics
  - Expand pool of extramural reviewers with knowledge of SGM health and health research
  - Explore the inclusion of SGM advocates on CSR panels

- Objective: Clearly explain and make available to SGM stakeholders the current policies that define minority or disparities populations.

- Objective: Consider what role, if any, NIH should play into trying to expand the current federal definition of minority or disparities populations.

- Objective: Implement the following IOM recommendation: “NIH should encourage grant applicants to address explicitly the inclusion or exclusion of sexual and gender minorities in their samples.” (page 10)

- Objective: Collect NIH workforce data to explore whether SGM populations are under-represented at NIH

- Objective: Develop and provide cultural competency training at NIH

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- Objective: Fund evaluation of SGM cultural competency training for health care providers to identify best practices in this area

Goal 3: **Create a community** of researchers and scholars who conduct research relevant to SGM health and well-being

- Objective: Convene state of the practice or state of the science conferences
- Objective: Enhance NIH presence at SGM conferences and special interest groups of large conferences such as APA
- Objective: Convene an SGM Health Research Advisory Council
- Objective: Facilitate the development of SGM researcher networks
- Objective: Fund mentoring for early career researchers or fellows interested in SGM health research

Goal 4: **Evaluate progress** on advancing SGM research health and well-being through NIH-supported research and training

- Objective: Prepare and disseminate annual reports (NIH Data Book) on standard NIH tracking variables as they relate to SGM research proposals: number of applications, success rates, etc.
  - Address inability to disaggregate QVR data by SGM variables of interest
  - Address inability to disaggregate RCDC data by SGM variables of interest
- Objective: Update SGM portfolio analysis on a regular basis
- Objective: In 2017 (or other date), convene an expert science panel to review the state of the science in SGM health research and NIH’s role in advancing the field.
- Objective: In 2017 (or other date), convene a panel of SGM stakeholders to review NIH’s mid-course progress on the Strategic Plan.

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Section III. The IOM Report and NIH

Note: Section III contains the Executive Summary from the above-named report.

This report of the NIH LGBT Research Coordinating Committee (RCC) identifies gaps and areas of opportunity for NIH to consider in response to the March 31, 2011 report of the Institute of Medicine 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 Institute of Medicine (IOM) report on LGBT health issues..." The IOM Report provides the first comprehensive overview of the health of LGBT populations in the United States and scientific research needs. With few exceptions, the IOM found that data and research on LGBT populations' health is quite limited.

The RCC conducted an analysis of the ongoing NIH research portfolio in LGBT health as a starting point for considering the IOM recommendations. By "mapping" the portfolio to the IOM recommendations, the RCC identified gaps and opportunities at the NIH. It is important to note that this analysis focused on the science and number of projects. Since the charge to the RCC did not include examining budgets, no financial data are associated with this analysis. In addition, the RCC examined the NIH research portfolio in the context of population variables such as age ranges, race, ethnicity, and what specific LGBT populations are involved in the ongoing research given that these issues were also raised in the IOM report.

Summary of Observations and Opportunities Identified by the RCC:
• The analysis of the NIH research portfolio on LGBT health indicated that much of the current portfolio is focused in the areas of Behavioral and Social Sciences, HIV/AIDS, Mental Health[1], and Substance Abuse. There appears to be relatively little research in several key health areas for LGBT populations including the impact of smoking on health, depression, suicide, cancer, aging, obesity, and alcoholism.

• Further, the portfolio analysis suggested a number of opportunities to expand the scientific knowledge base of LGBT health. These opportunities include, but are not limited to the following research areas: o Understand and address health inequities in LGBT populations and to increase health care-seeking behaviors

  - Further develop and standardize measures of sexual orientation and gender identity to inform LGBT health
  - Understand how health risks and protective factors interact and impact health over the life course

Understand resilience among LGBT populations, including how it develops, may protect health, and may buffer against the internalization of stigma and/or other negative experiences associated with sexual or gender minority status

  - Understand how minority stress, stigma and violence related to sexual orientation and/or gender identity influences health, particularly when combined with other factors such as race, ethnicity, immigration status, or low socioeconomic status

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  - Understand the increased incidence of certain diseases or conditions (e.g., eating disorders, obesity, sexually transmitted infections, etc.) in LGBT populations
  - Develop treatments and reduce risk for different mental health conditions including depression and suicide
  - Understand factors contributing to elevated rates of smoking, alcohol, and other substance abuse among LGBT populations including tailored prevention efforts
  - Better understand the differential risks for certain types of cancers including cervical cancer, breast cancer, anal cancer, Kaposi's sarcoma, and possibly lung cancer, among others
  - Transgender-specific health needs including those associated with transitioning and the safety and efficacy of surgical sex reassignment procedures as well as mental health and routine clinical care
  - Specific needs of children diagnosed as intersex and their families.
  - Cardiovascular, endocrine, and neurological effects as well as potential cancer risks of hormone therapy in transgender and/or intersex individuals

- A number of methodological issues need attention to help advance LGBT health research. It is critical to develop valid and reliable methods for asking individuals about their sexual orientation and gender identity in order to better understand LGBT health. Once developed, data collection of these variables can be more rigorously pursued in surveys, electronic health records, and other research settings. There is also a need to further develop methodological approaches to study small and/or hard-to-reach groups like LGBT populations.

- Training in LGBT health research as well as enhancing cultural competency of individuals working with LGBT persons in clinical settings and researchers is needed to enhance the understanding of LGBT health needs. Opportunities could be explored to collaborate with other components of the Department of Health and Human Services (HHS), particularly with regard to developing programs for enhancing cultural competency.

- Opportunities were identified to facilitate communication between the NIH and the LGBT research community to better understand the NIH mission as well as the NIH funding and review processes. How to encourage individuals engaged in research and/or training in LGBT health to compete for funding through various NIH mechanisms (both targeted and non-targeted to LGBT health) is an opportunity that should be explored.

- With approximately half of the NIH research Institutes, Centers, and Offices (ICOs) supporting LGBT health research in their portfolios, ongoing trans-NIH coordination and collaboration will be critical to address the noted gaps and opportunities as well as enhance communication throughout NIH and between NIH and other HHS Operating and Staff Divisions.

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In conclusion, analysis of the NIH research portfolio on LGBT health conducted by the RCC indicates a number of opportunities for advancing research in this area. In addition, valuable opportunities were noted for collaborating with other components of HHS to address critical health-related issues. Going forward, it may be helpful for the NIH to establish a trans-NIH mechanism in order to develop an integrated approach for pursuing these opportunities as well as monitor progress in this important area of public health.

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Section IV. NIH Portfolio Analysis FY 2012

Note: Section V contains excerpts from the above-named report only
The goal of this analysis was to assess the current NIH scientific portfolio relevant to LGBTI health… the focus was limited to awards issued in FY 2012 which provides only a snapshot of this inherently dynamic scientific portfolio… [A]n initial list of projects was developed using the Research, Condition, and Disease Categorization (RCDC) system and terms related to LGBTI health. This list was further refined through two processes. First, Boolean logic was applied to identify projects which contained combinations of terms relevant to LGBTI 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…. [T] analysis [was] limited to projects that include individuals who are lesbian, gay, bisexual, transgender, intersex, 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 but 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 LGBTI (or related) populations, only the projects from those disease/health portfolios that include LGBTI or related populations as participants are included in this analysis.

One example of this is the HIV/AIDS research portfolio. Although clearly LGBT and related populations are disproportionately affected by HIV and AIDS, there are also studies that focus, for example, on heterosexual populations 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. Only research projects that contain language in these sections describing plans to include LGBTI individuals were included in the initial project list; thus, RCDC's ability to identify relevant projects may be constrained by the manner in which investigators articulate their research goals and define their target populations. For this reason, the list of research projects may underestimate the true scope of the NIH research portfolio which includes LGBT participants. Once the list was compiled using the previously defined parameters, it was distributed to the NIH Planning and Evaluation Officers for feedback, including manual additions and deletions to the project list. The ICOs were asked to identify in each project which of the research areas highlighted as priorities in the IOM Report were addressed. 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 LGBTI populations (e.g., as mentioned above, HIV prevention interventions with heterosexual populations), or projects that were not active in FY2012.

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 since some large networks, centers, and other types of research support with multiple projects and subprojects were counted as a single project. In addition, even an individual R01 or other research project grant award often includes more than one study or protocol. Competing supplements are another mechanism by which additional populations (such as LGBTI individuals) or new study questions can be added to an ongoing award. Any supplements directly related to LGBTI health were also rolled up to 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 this is not a budget exercise.

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 the specific LGBTI populations (e.g., lesbians, gays, etc.). This task proved challenging as this information is generally embedded in sections of an award that lack structured data elements in NIH systems. These assessments also proved somewhat challenging due to variability in how investigators describe their target populations. These various labels were also documented and 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 LGBTI-Specific, LGBTI-Relevant, not LGBTI-Specific was slightly different from the classification used in the FY2010 LGBT Portfolio Analysis. This earlier analysis used the category of LGBTI-focused FOAs, which included FOAs that were exclusively devoted to LGBTI populations (such as PA-07-409, *Health Research with Diverse Populations (R01)*) as well as FOAs that were not limited to LGBTI populations but that mentioned these groups as one of several target populations (for example, FOAs on HIV prevention in vulnerable populations or underserved populations). This latter example would be classified as LGBTI-Relevant rather than LGBTI-Specific according the FY2012 definition. This more restrictive classification is likely to at least partially explain the smaller proportion project submitted under LGBTI-Specific FOAs (5.6%) in the FY2012 portfolio than LGBT-Focused FOAs in FY2010 (16.2%).

Gaps in Research and Areas for Future Study

The FY2010 LGBT portfolio analysis identified the 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 LGBT population groups and other health conditions was less well represented, and in general, the portfolio was not addressing many of the research gaps identified in the IOM report. The FY2012 LGBTI portfolio appears to be largely similar in size (after adjusting for the addition of LRP awards and intersex projects) as well the primary focus on HIV/AIDS research with MSM. When examined separately, intersex 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 disorders of sex development. Thus, across LGBTI populations, critical gaps in understanding the health needs and lived experience of LGBTI individuals remain.

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Further research is still needed in the following broad areas, as previously identified in the IOM report and the FY2010 LGBT portfolio analysis report:

- Health status, health risk (beyond HIV risk) and resilience, and healthcare utilization for LGBTI populations, particularly for lesbians/ bisexual women, transgender populations, and intersex populations.
- Health consequences of sexual minority status, including stigma, discrimination, social exclusion, and violent victimization.
- Social, emotional, and psychological development in LGBTI youth. There is a particular paucity of research in the NIH portfolio regarding transgender and intersex youth.
- Health issues for aging LGBTI populations, particularly for lesbians/ bisexual women, transgender populations, and intersex populations. Research is particularly needed to understand the long-term health effects of hormone therapy for transgender and intersex individuals.
- Access to and quality of healthcare and provider cultural competence for LGBTI populations.
- Methods of identifying LGBTI populations and the research and clinical implications of particular methods (for example, defining populations by sexual orientation vs. sexual behavior).

Regarding the mechanisms through which projects are submitted to the NIH, it is promising to see that LGBTI projects submitted to non-LGBTI focused FOAs are successfully competing for funding. At the same time, it is not clear that projects will address the gaps identified above if the bulk of applications are submitted to FOAs that do not identify these gaps as research priorities. The FY2012 portfolio does not include applications submitted to the 2012 “Research on the Health of LGBTI Populations” [R01, R03, R21], though it does include projects submitted to the 2007 PA that was the predecessor of these announcements (“Health Research with Diverse Populations” [R01]). It is possible that these FOAs will lead to an increase in projects that address the gaps highlighted above. However, given the similarity between the FY2010 and FY2012 portfolios, it is recommended that more highly targeted FOAs, preferably with budget set-asides, be issued that address both research and training (for example, an RFA for research on health needs of transgender populations). Without this type of highly targeted solicitation and budget investment, it is unlikely that the size or content of the NIH LGBTI portfolio will change significantly.

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Section V. NICHD DSD Activities

The National Institute of Child Health and Human Development conducted several activities to identify research opportunities in the SGM population of persons with disorders of sexual development (DSD). A Request for Information on DSD was released by NICHD in the winter of 2014; 26 responses were received. The RFI data were analyzed internally at NICHD and were used to plan a workshop that was held in March 2014. Thirty-seven subject matter experts participated.

These activities culminated in the development of an NICHD internal document, an Initiative Report, authored by Dr. Lisa Freund, dated 13 June 2014: Multidisciplinary Approaches for Developmental Research with Individuals with DSD. Excerpts from that Report follow.

“In order to identify the research gaps and needs for the care and treatment of infants, children, and adolescents with DSD, an expert workshop, *Growing up with DSD: Critical Developmental Issues for Children and Families Affected by Disorders of Sex Development,* was convened by NICHD, with additional support of the Office of Rare Diseases Research, in March 2014.

“The meeting gathered a multidisciplinary group of clinical and research experts who described and discussed: a) current knowledge of the etiologies of DSD as well as current clinical care and counseling for affected children and adolescents and their families and families practices in the clinical care and counseling for children and adolescents with DSD and their families; b) significant knowledge gaps and research needs, in order ultimately to better inform all aspects of care for affected children and adolescents and families and c) specific research questions, to advance the field. Input from affected individuals and families as well as other interested individuals and organizations was sought in several ways. Advocates' and activist representatives participated in all planning of the workshop and a NICHD RFI solicited comments and recommendations, a summary of which was provided to workshop participants before the meeting began. Major themes emerging from the workshop discussion and from the RFI comments were, in many instances, virtually the same, such as the needs for a stronger evidence base for diagnosis, prognosis and assessment of outcomes and for full, accurate, and readily-understandable communication among affected individuals, families and clinicians to ensure informed decision-making…

“Topics of research for the four major identified areas for DSD are listed below but are not necessarily limited to this listing:

- Improving Diagnosis of DSDs:
    - Novel genomic approaches for increasing diagnostic accuracy
    - Innovative techniques for more timely and accurate diagnoses

- Genitosurgery/Gender Assignment Outcomes:
    - Outcomes for newer surgical techniques (both short-term and long term):
    - Frequency and severity of complications
    - Assessment of physical, developmental psychosocial outcomes, quality of life, family functioning---both short-term and long-term

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  - Quantitative methods for measuring surgical and/or treatment satisfaction
  - Timing effects of surgery/gender assignment (early vs. late vs. no surgery) on outcomes
  - Identification of predictive factors that can be used for more accurate gender assignment
  - Prospective studies to analyze outcomes of gender assignment
  - Methods for fertility preservation

- Psychosocial and Functional Impacts on Development with DSD:
  - Developmental impacts of DSD condition and/or hormone treatment on social development, gender development, cognitive and emotional development from infancy through young adulthood
  - Identification of impacts on the family (identification of stressors, use of supports, dynamics, parenting) ; how those impacts affect child outcomes
  - Developmental impacts of DSD conditions and/or hormone treatment on functional outcomes such as friendships and school achievement
  - Predictors of and factors affecting gender satisfaction/dysphoria during developmental periods
  - Factors affecting outcomes associated with the adolescent transition to adulthood
  - Development and demonstration of effective methods for preparing adolescents transitioning to adulthood for self-management of condition (medically, socially, interpersonally, romantically)

- Improving Clinical Management of DSD
  - Clinical trials for hormone supplementation or replacement treatment:
    - Determination of optimal timing and dosage
    - use of genetics to optimize treatment
    - associated cancer risks
  - Standardized tools for describing the physical phenotype
    - e.g., digital photography and standardized measurement algorithms
  - Development of effective informational/educational materials for families and patients that are comprehensive, developmentally appropriate, and understandable
  - Development of effective methods for clinician communication with patients and families at diagnosis, when making surgical/gender assignment decisions, during clinical follow-up and management."

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Section VI. LGBTI RCC Outreach Activities

Table 1: Description of Outreach Activities

Activity name	Activity date	In person?	NIH Initiated?	Participants invited by NIH?	Characteristics of participants	Number of non-NIH participants
A. NIH LGBTI Listening Session	27 June 2013	yes	yes	yes	NIH-identified leaders of advocacy groups	12
B. Brainstorming Sessions on Training 1 & 2	Fall 2013	no	yes	yes	NIH funded researchers and university faculty	25
C. Advocacy Group Listening Session	15 Nov 2013	no	yes		Members of NBGMAC & BGRG	10
D. NIH Request for Information	Fall 2013	no	yes	NA	Self-selected	140 responses
E. Transgender Health Research Listening Session	10 January 2014	no	yes	yes	University faculty and persons from advocacy organizations	14
F. NIH Program Staff Input Session	29 Jul 2014	yes	yes	yes	NIH program officers & analysts	0 (5 NIH staff, 3 who were also RCC members)
G. NIH Supported SGM Researchers Listening Session	29 Jul 2014	no	yes	yes	NIH funded SGM researchers	9

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Table 2: Data collection and Analysis for Outreach Activities

Activity label and name	Type of data collected	Data collection method(s)	Data analyzed	Recorder	Analyst(s)	Participant Review
A. NIH LGBTI Listening Session	Narrative statements, Q&A, conversation	Notes taken by hand, position papers submitted Session videotaped???	Comments (nonverbatim) by individual participants	Alexander	Hamann	
B. Brainstorming sessions on Training 1 & 2	Narrative statements, conversation	Notes taken by hand	Comments (nonverbatim) by individual speakers	Hamann	Hamann	Member checks of analysis
C. Advocacy Group Listening Session	Narrative statements	Notes taken by hand	Comments (nonverbatim) by individual participants	Alexander	Hamann	Member check of transcript
D. NIH Request for Information	Letters, written comments	Electronic submissions	Verbatim submissions by individuals or groups	NA	Nagy, Hamann	
E. Transgender Health Research Listening Session	Narrative statements, conversation	Notes taken by hand	Summary of comments (not linked to individual speakers)	Hamann	Hamann	Member checks of analysis
F. NIH Program Staff Input Session	Facilitated Q&A, conversation	Notes taken by hand	Comments (nonverbatim) by individual speakers	Hamann	Hamann	Member checks of transcript
G. NIH Supported SGM Researchers Listening Session	Narrative statements, Q&A	Notes taken by hand	Comments (nonverbatim) by individual speakers	Hamann	Hamann	Member checks of transcript

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Section VI.A. NIH LGBTI Listening Session

NIH prompts included in the invitation to participate

- Gap areas with respect to LGBTI health research
- Methodological or other challenges to addressing these gaps
- Scientific advances on which further research could be built
- Effective ways to engage with the LGBTI health research community

NIH verbal prompts at the beginning of the meeting

- Issues of relevance to the LGBTI community
- Highest priority LGBTI research issues
- Terminology and classification

Tabular summary of contents

RCC Strategic Goal	Activity Prompt	Analyst-coded category	Participant-named items
Expand the knowledge base	Highest priority LGBTI research issues	Specific populations	Two-Spirit, DSD, urban & tribal Native Americans
		QOL	
		Life course	
		BSSR	
		Specific topics	Tobacco, drugs, suicide, hormone therapy (non DSD), stress & physical health, DSD, gender dysphoria, cancer risk, cancer treatment, survivorship, intersectionality (race, culture, sexual orientation), PTSD, depression
		Methods	Community based (broadly defined)
			Patient-centered

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Remove barriers	Terminology and classification	Epidemiology & demographics	
		Funding	Disparities designation (formal)
			Disparities designation (supplements, set-asides for training & research)
			Amount of funding
			Review panels
			FOA development
		NIH structure & environment	NIH Office for LGBTI Research
			Data ownership among Indian tribes
			NIH staff diversity
			Minority reps on Advisory Boards & Councils
			IC commitment
			Trans-NIH research and IC interests
Create community	Issues of relevance	Supportive institutional (home) environment	
		Supportive network	Interdisciplinary networks, mentoring
		Knowledge of LGBTI health & Health research issues	

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Section VI.B. Brainstorming Sessions on Training 1 & 2

NIH prompts

- What NIH programs and approaches are working well?
- What are the best practices that you have identified?
- Where should the NIH be going to enhance training for LGBTI health research?
- How do we support the inclusion of LGBTI health research issues throughout the life of projects by both trainees and more senior researchers?
- What do you already know about NIH's existing training and career development programs?
- What are the barriers to entering LGBTI health research?

Narrative Summary

Session 1.

There are multiple groups of people of interest for NIH training and career development. There are likely to be differences in the training needs of each group.

- LGBTI persons who might become LGBTI health researchers
- LGBTI persons who might become health researchers but not in LGBTI areas
- Non-LGBTI persons who might become LGBTI health researchers

To be successful as an NIH PI, especially as a New Investigator, it is helpful if the applicant has

- Knowledge of NIH research areas of interest
- Knowledge of NIH mechanisms and opportunities
- Preliminary data
- Experience on a training grant or as a member of another PI's grant
- Mentoring
- Interdisciplinary research skills, including the ability to identify interdisciplinary topics, to select and attract interdisciplinary team members, and to design interdisciplinary studies
- Grantsmanship

General training in all of these areas is needed, as well as specific training in how these areas are related to LGBTI research. Relevant resources vary widely by university. Some of this training could be accomplished by improving and adding to information on the NIH webpages.

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Targeted mechanisms from NIH (either targeted to LGBTI researchers or LGBTI health research) are more likely to advance researchers and the field than non-targeted mechanisms.

An NIH-supported conference on the intersection between basic research and clinical research in the area of LGBTI health with an emphasis on interdisciplinary research approaches would advance the field.

To advance the field of LGBTI health research, basic epidemiologic data are needed. NIH could play two roles: developing a funding opportunity for studying best practices in LBGTI epidemiology and leading or contributing to federal-level efforts to standardize terminology around LGBTI identification and health issues.

The feasibility of dedicating oneself to LGBTI research is unclear because of political risks, social risks, and funding uncertainties. Cultural competence training is needed.

NIH is the appropriate federal-level agency to support and enhance LGBTI health research.

<u>Session 2.</u>
Improvement has been observed in the use of appropriate LGBTI terminology by NIH staff.

NIH has supported LGBTI research and training awards. The number of LGBTI topics and the number of NIH Institutes and Centers supporting LGBTI health research has been limited.

There are two populations of interest in regard to training: persons interested in conducting LGBTI health research and persons who identify as LGBTI who are interested in conducting health research, although perhaps not in LGBTI areas. Their training needs are likely to differ.

Potential LGBTI investigators and applicants face significant challenges in becoming NIH independent researchers:

- Scarcity of expert mentors
- Scarcity of existing R01s in LGBTI issues for sign on as collaborators or trainees
- Lack of population data and preliminary data to support applications
- Lack of large pool of LGBTI investigators to serve on review committees
- Lack of review experience by potential and unsuccessful applicants
- Review committee members who are poorly informed about LGBTI health research issues and research methods

LGBTI targeted mechanisms are more likely to result in funding of LGBTI researchers and LGBTI research than non-targeted mechanisms.

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Standardization of terminology in the LGBTI field is needed quickly, especially in regard to variables for gender identity and sexual orientation. HHS and other federal agencies do not appear to be coordinated in relevant efforts.

The complexity of NIH funding mechanisms and operational processes leads to insufficient knowledge and awareness of various NIH activities and mechanisms that could support LGBTI research and LGBTI researchers. There is no systematic, electronic way to identify awards in LGBTI topic areas.

Stigma associated with identification as a researcher interested in LGBTI research or as a medical researcher identifying as an LGBTI person inhibits some people from pursuing LGBTI research as a career. Many people who identify as LGBTI or who conduct LGBTI research do not study and work in supportive environments.

Mid-career LGBTI professionals would like to become NIH investigators but have difficulty getting an independent, large award. It is difficult to identify a senior investigator to work with them. The senior investigator would bring grantspersonship, existing funding, and research design to the partnership, and the mid-career investigator would bring LGBTI content knowledge.

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Tabular Summary

RCC Strategic Goal	Category (coded by analyst)	Representative Comment
Expand the knowledge base	Interdisciplinary research and training	It would be wonderful if there was a mechanism to prepare people to use interdisciplinary approaches in specific LGBTI content areas.
		The fact is there is only a tiny pool of behavioral or psychosocial researchers contributing to our understanding of quality of life outcomes in DSD and even fewer of these are scientist-practitioners. A related issue follows: everyone believes that interdisciplinary research is critical, but no one is formally trained in interdisciplinary approaches to DSD research.
		What works well is the proximity of ongoing clinical care and research, particularly the translation of basic research to the bedside.
Remove barriers	Distribution of information about NIH funding opportunities	In my institution, we have a good program where we bring people together to facilitate research. We would like to have NIH attend and speak about grant writing and NIH funding opportunities.
		Can NIH connect research scientists with opportunities for LGBTI research?
		Could NIH provide a guidebook about using NIH resources, including different grant opportunities, for LGBTI career development and research? We need to encourage people to think about how their work can be brought into LGBTI. NIH might ask the people who are on this call to answer the question, How can a grant you are considering be responsive to LGBTI issues?
	Training for study section members	How are reviewers trained? One of my concerns is that, in LGBTI health research, we often have to use methodologies that are unusual and national data sets about LGBTI health are not available.
		The IOM report is a keystone in helping people understand LGBTI as a disparities area and in legitimizing the area. Can the Executive Summary of the IOM report be sent to reviewers who are going to review LGBTI applications? There may be other ways of making the reviewers aware of the issues highlighted in the report.
		Some LGBTI projects and proposals that do not reflect current knowledge are approved because the reviewers did not recognize that the proposal used outdated terminology or methods. When these flawed projects are funded, they magnify the problem of lack of information through publications and presentations. This underscores the need to train investigators who become reviewers.

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	Epidemiology and population data	We are also constrained by the lack of preliminary data because health records and national surveys do not identify LGBTI. How can we overcome the lack of preliminary data?
		NIH could sponsor an RFA for studies about reaching LGBTI communities and asking questions that facilitate self-identification in surveys.
		An RFP that would set up researchers to compete to learn about best practices in LGBTI survey research is a good idea.
		LGBTI researchers are in a methodological Catch 22. We receive criticisms of our applications in regard to outcomes. We are also constrained by the lack of preliminary data because health records and national surveys do not identify LGBTI. How can we overcome the lack of preliminary data?
	Cultural competence	How do we inculcate a supportive climate for LGBTI graduate students and LGBTI research? We have lots of students who say they are scared about coming out because of what seniors might think about them or how their lab mates would react to them.
		Cultural competency training is needed at the university level.
	Targeted mechanisms to fund LGBTI research and LGBTI researchers	It would be helpful if NIH would encourage FOAs, RFAs, and PAs that promote LGBTI research. Could NIH develop T32s specifically for LGBTI?
		If NIH is trying to build LGBTI researchers, you will have to have specific grants in that content area.
		The K23 is a good pipeline for young investigators to gain experience and get preliminary data to support an R01 proposal.
		In regard to the current Program Announcement for LGBTI research, the R01, R03, and R24 are mentioned but there is no mention of training mechanisms, even though the bullets talk about training providers.
		NIH career and training opportunities should have LGBTI added to that list of qualifying disadvantaged backgrounds.
	Federal policies	I recognize that the definition of under-represented minorities is currently set, but can NIH be a leader in developing the field of LGBTI research without changing the policy or the law… Can NIH facilitate discussions that might lead to policy changes?
		Does NIH have a specific policy that calls for justification if sexual orientation is excluded from clinical research, similar to the exclusion by race or ethnicity? It would be good for reviewers and applicants to have to consider exclusion by sexual orientation.

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Create a community	Mentoring	NIH should connect young investigators with expert mentors earlier in their careers. I am fortunate to be in an institution that has faculty with research and mentoring experience, but how do you reach potential young investigators who do not have access to faculty with expertise in LGBTI research, mentoring, or grantsmanship? NIH could create structures that support mentorship, particularly a program that allows protected time for senior mentors and allows connections to develop.
		We need to train junior investigators to become mentors. Resources to support mentors are limited or unavailable. From a global standpoint, NIH might reconsider the philosophy of not compensating mentors.
		One very important way to address mentoring for those LGBTI people whose institutional resources are limited in expert LGBTI mentors is to award travel grants for new talent to visit successful LGBTI talent.
		We need to normalize LGBTI research so people believe that they can build a career. But we also have to consider the professional climate. How do we inculcate a supportive climate for LGBTI graduate students and LGBTI research? We have lots of students who say they are scared about coming out because of what seniors might think about them or how their lab mates would react to them. NIH must think about mechanisms for welcoming LGBTI research: how to make it inviting, exciting, credible. Could NIH think about disbursing funds to people meeting the highest standards in professional conduct? Finally, in this time of limited resources, can sexual orientation be included in ongoing and other studies?
Evaluate progress	Tracking of LGBTI awards	It would be great if there were a systematic way to keep track of NIH LGBTI research awards.

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Section VI.C. Advocacy Group Listening Session

NIH prompt

- What is working well with respect to NIH's efforts to advance LGBTI health research?

We note that there were no responses relevant to the prompt, although there was endorsement of the IOM report.

Tabular Summary

RCC Strategic Goal	Analyst-coded category	Comments by participants
Expand the knowledge base	Specific populations	Need research on urban environments
		Health needs of LGBTI people of color in rural areas
	Life course	There has to be a focus across the lifespan, a more developmental approach
	Specific topics	Resilience, identity & outcomes, healthcare seeking, relationships with providers, childhood trauma, effects of racism and prejudice, cultural acceptance, religiosity, preventive care, interventions, social determinants of health, models of care
	Methods	Community-based participatory research should be a model for LGBTI centers of excellence
Remove barriers	Epidemiology & demographics	How to partner with insurance companies to use data already collected
	Funding	NIH should increase research funding, especially for black MSM
	NIH structure & environment	NIH should have representatives at LGBTI advocacy group meetings
		LGBTI populations should be designated as health disparities
		Lack of synergy between SAMHSA, CDC, NIH, HRSA, and HUD
		Investigators should be encouraged to consider LGBTI subpopulations in their research protocols
Create community	Supportive institutional (home) environment	Response to NIH FOAs depends on support at home institution
		Build capacity for LGBTI research at under-resourced institutions
		Target workforce development efforts to MSIs & HBCUs
	Supportive network	Make research findings more accessible, easier to translate into practice
	Knowledge of LGBTI health & Health research issues	Need to build capacity among folks who are not biomedical researchers but who make contributions to biomedical research (education researchers, policy researchers)

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Section VI. D. NIH RFI Question about Challenges to Data collection and Analysis

NIH prompt

- NIH is requesting input [about]… Methodological or other challenges to data collection and analysis for small and/or heterogeneous LGBTI populations

Narrative Summary

One major challenge in epidemiology studies is simply populating the studies. In this population, probabilistic based sampling may not be possible without considerable expense that is realistically beyond most budgets.

Other respondents suggested that collecting LGBTI data is not, in and of itself, problematic; rather, external policy issues – tradition, willingness, and politics – present the largest barriers to such data collection. Tellingly, bias, discrimination and tradition have excluded LGBT individuals from being integral components of research protocols as a normal and expected set of populations required to be represented in any credible research protocol.

Specific barriers exist to engaging LGBTI communities of color (due to perceptions of racism, discrimination, and exploitation), individuals in rural areas (who may be unconnected with any resources through which they can be identified), and the economically distressed (who may have work schedules that preclude participation in a study during regular clinic hours or who may lack Internet access needed to participate in an on-line survey).

Terminology is a barrier because surveys often fail to accurately assess both a participant's sexuality and gender identity with accuracy, there is no standardized terminology, especially for transgender respondents, and data on sexual orientation and gender identity are not routinely collected in medical care data sets. There needs to be much more emphasis and leadership at the federal level on collecting these data as a normal part of standard demographic data collection.

Reliable methods for sampling from the LGBTI population are lacking. Probability samples might produce too few LGBTI individuals to allow for examination of within group analyses or between sub-groups of the LGBTI population. These sub-group analyses are critical as existing data from community samples suggest large differences among sub-groups. As such probability samples need to over-sample LGBTI individuals and there will always be a need for other sampling approaches to recruit large samples of LGBTI individuals. In this regard, we need further methodological research to determine that pros and cons of various sampling methods such as convenience samples, snowball samples, respondent driven samples, etc. Absent this type of data, LGBTI focused grant proposals are often at a disadvantage relative to studies of other populations where validated sampling methods are established.

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Another methodological challenge resides in research design. The choice of an appropriate survey method, for example, can both minimize non-response and improve accuracy and validity of responses. As a group, LGBTI persons are, at best, subject to extra scrutiny and, at worst, the targets of stigmatization and violence. Consequently, many have reason to be vigilant, to withhold their identities, or to misdirect others about their identities. Some modes are more likely to elicit these defensive behaviors than others.

Other specific barriers were identified for research about transgender health.

Tabular Summary

NIH mission framework: Fund, support, and conduct **extramural and intramural research**

RCC Strategic Goal: **Remove barriers** to NIH-supported research about SGM health and well-being

Category (coded by analyst)	Sub-category (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Populating studies (participant perspective)	Reluctance to self-identify	
	Inability to self-identify (Inappropriate or non-standard terminology)	
	Little access to research studies	
	Wariness about research participation	
Populating studies (researcher perspective)	Sampling from populations of unknown distributions	
	Sampling from small populations	
	Locating potential subjects	
	Inappropriate or non-standard terminology	
Other methodological challenges	Little baseline epidemiology	
	Unknown interactions between research design and participant response	

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Section VI.D. NIH RFI Question about Training

NIH prompt

- NIH is requesting input [about]… **Training** in LGBTI health research and enhancing the **cultural competency** of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency.

Narrative Summary
First we note that the RFI question itself addressed two different kinds of training: training for NIH researchers and potential NIH researchers about conducting SGM health research and more general training about SGM health for multiple groups, referred to as cultural competency. Most of the comments addressed cultural competency training.

This question was treated broadly by the respondents, and comments went beyond recommendations for NIH collaboration with other federal agencies to develop training. Often the responses served to confirm the importance of the topic raised or to validate the topic by personal experiences. Respondents identified specific groups of people who needed training, made suggestions about the content or curriculum of training, and suggested specific training models. Respondents also addressed the narrow question of potential partners to NIH, including federal and other agencies and groups, who could both develop and deliver training. Recommendations and suggestions about NIH funding and support for training were put forward. Finally, suggestions were made about the evaluation of training and career development programs.

There was an emphasis on the need for training of health care providers, including medical students, physicians, nurses, psychologists, and others. The need for training for providers regarding multiple LGBTI populations, with an emphasis on transgender populations, was endorsed. Respondents endorsed training for NIH funded researchers and trainees.

In regard to curriculum for cultural competency training, responses were numerous. Suggestions regarding the terms used to identify training programs (cultural competency versus cultural humility versus cultural awareness) as well as training in appropriate nomenclature for LGBTI populations and issues were made. A wide range of curriculum topics was also put forward, including standards of care, specific medical and behavioral conditions, societal issues, and provider interactions with patients and families. Training programs from the following federal agencies were mentioned: SAMHSA, HRSA, HHS, and ACF. Boston University, the University of Central Florida, and the Fenway Summer Institute were mentioned as having model programs.

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Some of the agencies that were reported to have good training models were also recommended as partners to develop and deliver training. Many other organizations were mentioned. A major addition in regard to partners was the need to include persons from LGBTI populations and persons from organization serving LGBTI populations in development and delivery.

Respondents endorsed multiple NIH mechanisms that could support LGBTI research, including set-aside or protected mechanisms for researchers addressing LGBTI health topics, mentoring, and loan repayment programs. Recommendations for administrative changes at NIH that support LGBTI training included the designation of LGBTI populations as disparities populations, the advancement of standardized terminology and definitions, the development of LGBTOI leadership within NIH, and the creation of an NIH office dedicated to LBGTI health research.

Finally, multiple respondents endorsed the need for evaluation of cultural competency training in regard to content, delivery, and outcomes.

Tabular Summary

NIH mission framework:	Provide **career development and training** for researchers.
RCC Strategic Goal:	Create a **community** of researchers and scholars

Category (coded by analyst)	Subcategory (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Groups needing training	Health care providers	Training of psychiatric/medical/psychological practitioners and researchers would have a ripple effect across LGBTQI communities and would transform the level and quality of care for the community. This should be a top NIH priority and should include integrated involvement from all members of the LGBTQI community with the support of academic and medical institutions. There is a grave and urgent need to train doctors in the all aspects of care for trans people which should include care for the entire lifecycle.
	Researchers	We urge the NIH to create a comprehensive research-training program that would raise awareness of LGBT health issues among researchers. Training the next generation of post-doctoral researchers to compete successfully for NIH grant funding provides the strongest opportunity to increase LGBTI research. Such a program could encourage researchers to include sexual and gender minorities explicitly in their samples, using the NIH policy on the inclusion of women and racial and ethnic minorities in clinical research as a model.
	Others	Diversity training specific to LGBTIQ needs to be mandatory for CPS, DCFS workers who deal with youth who have been made homeless by their LGBTIQ affiliations.
Curriculum suggestions		I would encourage NIH to shift the language away from "cultural competency" and adopt "cultural sensitivity" or "cultural humility." I would love to see NIH team up with CMS and mount

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		a campaign to require all providers at hospitals or centers that receive Medicaid/Medicare funding to undergo a full two-day training that covers: 1. Cultural humility with LGBTQ patients 2. Challenging provider assumptions about patients' gender, sexuality, and behaviors in patient-provider interactions, especially in sexual history taking. 3. Asset-based approaches to LGBTQ health disparities (addressing homophobia and stigma and the reasons behind most disparities) 4. The important role of healthcare providers in the developmental stages of LGBTQ youth 5. National resources for providers (GLMA, HRC's Healthcare Equality Index, etc.)
		Investing in the training of health professionals may both facilitate the implementation of transgender health interventions and be an intervention itself. Funding initiatives to research the impact of providing future and current health professionals with transgender training, and training on the nature and impact of discrimination, might encourage health program academic accreditation bodies to institutionalize such training in health schools. Training of this nature should incorporate intersectionality, as well as principles of cultural humility, reflexivity, and transgender respect to create dialogue about partnering with marginalized individuals and communities.
Training models		SAMHSA has developed tools to promote cultural competency in behavioral health services providers. These tools include a resource kit on LGBTQ health issues and a brief aimed at educating policymakers, administrators and providers on providing services and supports for LGBTQ youth.
		Health Resources and Services Administration (HRSA) awarded $248,000 to create a National Training and Technical Assistance Center to help community health centers (CHCs) provide improved care for LGBTQ patients. The center will work with CHCs throughout the country to train health services professionals on working with LGBTQ populations.
Partners for developing and delivering curriculum		The NIH should not only collaborate with other federal agencies, but also with groups that provide guidance to clinical training programs, e.g. Association of American Medical Colleges, Association of Schools of Public Health, etc. to support the development of training curricula and to evaluate the progress of schools/programs towards an inclusive and welcoming environment for LGBTQ students, faculty, and staff.
		Partner with the non-profit foundations that serve this community (NCTE, NGLTF, Pride Foundation, etc.), academia and the professional organizations for the helping professions (NASW, APA, AMA, etc.). Encourage undergraduate and grad schools to offer courses and programs in LGBT studies (similar to Women's Studies).
NIH mechanisms that could support training and career		Consult with LGBTI health care providers (there are a lot of organizations: Lyon-Martin Clinic, Mazonni Center, Callen-Lorde Clinic, GLMA, Rebellious Nurses, Transgender Health Initiatives,

development		unaffiliated individuals, etc). Collaborate with LGBTI organizations (student, social, health, and community) to arrange competency trainings for providers working in clinical settings, these are very useful and low cost ways to develop cultural competency.
Policy, administrative, & personnel changes at NIH that would support training		Add LGBT as a disparity population and allow for postdoctoral funding opportunities in disparities to include LGBT issues.
		We need training grants at the graduate and post-doctoral levels in LGBT health research.
		We support extending the extramural loan repayment program to assist students who choose to study LGBT health issues within the context of graduate programs for Community Health Education.
		Offer grants, internships, fellowships, supervision and independent study at the NIH and partners for those who have recently earned their undergrad and graduate professional degrees who are seeking experience with the LGBT community.
Evaluation of NIH training and career development		The stark reality that we do not know what components constitute a successful cultural competency training program is an ongoing challenge. Adding to the difficulty, we do not know the effective individual or institutional dose, what outside supports are needed for institutional change, or what factors make some trainers more and less successful. All of these questions can be answered with research.
		Cultural competency of researchers and individuals working with LGBTI persons in clinical settings is necessary and ought to be ongoing. We identify three questions about cultural competency that could benefit from further attention: 1. Are scholarly perspectives from outside of medicine, for example sociologists and/or bioethicists, included in cultural competency training programs? 2. Are patient perspectives included in cultural competency training programs? If so, are all age groups represented? 3. How are cultural competency training programs assessed?
		Cultural competence training is repeatedly suggested as a valid way to change healthcare providers' attitudes and treatment of LGBT patients, but there is no data to suggest that this method is successful in achieving changes in provider-patient interactions. We need research on best practices. In the meantime, trainings are offered all over the country with simple pretest/posttest measures and these may be accomplishing nothing of value.

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Section VI.D. NIH RFI Question about Engagement

NIH prompt

- NIH is requesting input [about]… Effective ways to engage **with the LGBTI health research and advocacy communities,** which include the broad range of populations that may be encompassed by the term LGBTI.

Narrative Summary

In this section of the RFI, respondents were asked about engagement with the LGBTI health research and advocacy communities. Recommendations were made about how NIH could change policies, practices, and structures to be more welcoming to the communities, to locate the communities, and to engage with the communities. NIH staff were encouraged to demonstrate cultural competence and knowledge of LGBTI populations and health issues, particularly by changing terminology and demonstrating respect and support for LGBTI communities and advocates. NIH's use of the term, transgendered, rather than the term, transgender, was addressed.

In regard to collaborating and interacting with LGBTI communities, NIH was encouraged to support community-based participatory research and to include LGBTI experts in designing and reviewing research agendas and proposals. Specific groups and contact information, such as website address, was provided by some respondents.

Respondents recommended modifications to the administrative and programmatic structures at NIH to facilitate engagement with LGBTI communities. There was interest in an NIH office of LGBTI health, in establishing an LGBTI liaison at every IC, in convening meetings dedicated to LGBTI research, and in establishing an LGBTI research advisory group.

Several respondents endorsed the IOM recommendation to modify NIH policy such that LGBTI populations are mandated to be included in studies or that the exclusion of LGBTI populations must be justified.

Recommendations about NIH collaborations with other federal and non-federal agencies were also put forward.

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Tabular Summary

NIH mission framework: Fund, support, and conduct **extramural and intramural research**.

RCC Strategic Goal : **Remove barriers** to research

Category (coded by analyst)	Subcategory (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)	Under NIH control?
Demonstrate cultural competence and knowledge of LGBTI populations and health issues	Change NIH terminology	I would recommend the medical researchers immediately drop the use of LGBTI and do not force people into association with that terminology. To do should be seen as a professional ethics violation. If you truly want the populations you will start from square one and use neutral terminology like same sex attracted and sex and gender diverse	Yes
		First – do not use the word "Transgendered" – it is inappropriate terminology. We are all gendered at birth – without our consent. But we don't say someone is "female-ed" or "male-ed" to identify their gender identity... nor should we say "transgender-ed" to identify the gender identity of persons who are transgender. The terminology will alienate people. It would be much more meaningful, and the dataset much more rich, and more reflecting of the actual community, if you looked beyond the binary construct. Many folks in the community identify as beyond the binary, non-binary etc. Indigenous people like myself who identify as Two Spirit do not fit neatly in these categories.	
		Intersex persons are not by definition a particular orientation – as are lesbian and gay folk. There is a wide variation in expression for all intersex persons regardless of their particular genetic appellation. DSD is a genuine turn off for all intersex persons. We are not disorders. No matter how you dance around this subject, in the end, medical folk using DSD are unconsciously putting intersex folk in a "let's fix it" box.	
		Careful classification is needed for a rigorous approach to this heterogeneous community. Specifically, transgender patients/gender identity patients can be divided into those who depend on medical intervention to achieve the desired gender and those who do not. The latter might be best be addressed by a welcoming, tolerant provider approach while the former require a knowledge set beyond tolerance. Although the categories often are divided along social lines, some barriers to care relate to treatment requirements. For example transgender and intersex patients require access to good endocrine care and	

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		good surgical care that might not be needed for other gender/sexual minorities. As well, the risks/benefits of those interventions need to be assessed independently.	
	Demonstrate respect and support	The NIH should promote the development of a culture, infrastructure, and processes that work towards closing the gap in care that currently exists for the LGBT and DSD-affected populations. For example, we strongly encourage the NIH to include cultural sensitivity material as part of the Responsible Conduct of Research training required of NIH-funded researchers. Such national requirements will support the development of institutional climates welcoming of diversity, including LGBT and DSD affected individuals	Yes
		These populations need to feel that they are safe to discuss and be open about their identity in public health organizations or they will be ineffective with data collection relating to their specific issues. Creating safe zones at all public health organizations will increase the reliability of this population to express themselves in a way that effectively genuinely honestly depicts their actual health needs.	
		These populations need to feel that they are safe to discuss and be open about their identity in public health organizations or they will be ineffective with data collection relating to their specific issues. Creating safe zones at all public health organizations will increase the reliability of this population to express themselves in a way that effectively genuinely honestly depicts their actual health needs.	
Collaborate & interact with target populations	Support community-based participatory research	Utilize Participatory Action Research/Community Based Participatory Research to engage various LGBT communities in the struggle to enhance their health and well-being. Ask the communities what they think are the issues that most impact their health and well-being and truly partner with them in addressing what can be addressed.	Yes
		Increase investments in community-based participatory research (CBPR). CBPR is a collaborative approach to research that equitably involves all partners – researchers and subjects – in the study process. This collaborative process starts with the selection of a research topic that incorporates community input. This approach can be used to engage diverse sub-populations of LGBTI	

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		individuals and communities.	
	Reach out to specific populations and groups	You need to approach LGBT advocacy organizations - local, state and national (not just national ones) - and seek anonymous input from their members.	Yes
		We recommend continuing to reach out for community input to experts through listening sessions and presenting at community gatherings and at student mentorship events.	
		We believe that marginalized populations mentioned above may often times be utilizing resources at clinics, non-profit organizations, and community centers. Connection to such institutions is necessary to engage with LGBTI persons in regards to health research.	
		Use CTSAs for community engagement (but not exclusively)	
Modify NIH administrative and programmatic structures		Establish an LGBTI research advisory body to regularly engage external stakeholders	Yes
		Establish an office of LGBTI health	
		Nourishing a strong cadre of openly LGBTI leaders at NIH is the single best strategy for ensuring information channels are easily accessible to outside experts. We recommend appointing an LGBTI liaison at every Institute. Initiatives are helpful, but, especially at NIH, information is transmitted via personal connections, and larger communication initiatives can’t replace the value of having an openly LGBTI liaison at every Institute.	
		There is currently no address at NIH for transgender related research. The current PA advocates for research in the existing categories for NIH that might have impact on transgender individuals. An approach that examines transgender health care more broadly would be cross discipline currently and might seem to be part of the mission of any institute. NIH should designate a specific home for transgender (and perhaps also intersex) research in order to encourage individuals engaged in research to submit transgender oriented proposals.	
Modify NIH policy to mandate inclusion of LGBTI		We understand that the overall health and wellness of the LGBTQI population is impacted over the life course by a wide array of issues. By widely implementing	Yes

populations and data in clinical research		the IOM's recommendations mandating the inclusion of LGBTQI people and LGBTQI data in all studies (or justifying their exclusion), the NIH can see that this depth of research is achieved.	
Update NIH and sister agency reports with contemporary LGBTI research data		One of the continuing disappointments is that researchers provide information and new knowledge but that doesn't seem to update federal reports. This is an opportunity for NIH to work with the CDC and SAMHSA to harmonize their reports with the changes in our knowledge base.	Partially
Collaborate with non-research organizations		The National Endowment for the Arts, National Endowment for the Humanities, and NIH should collaborate to integrate humanistic and cultural intervention as a way to not only enhance cultural competence but deepen cultural awareness, humility, and understanding for scientists and support staff affiliated with those institutions.	Partially
Advocate for federal policy changes		Spend much more time talking about the duty and obligation of the United States government to outlaw discrimination based on sexual orientation and gender identity to create a safe environment for our development and lives.	Partially

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Section VI.D. NIH RFI Question about Communication

NIH prompt

- NIH is requesting input [about] … Effective ways to enhance **communication** between the NIH and the LGBTI research community to enhance practical understanding of the NIH mission, as well as the NIH funding and review processes, and encourage individuals engaged in research and/or training in LGBTI health to compete for funding through various NIH mechanisms (both targeted and non-targeted to LGBTI health.

Narrative Summary

In this part of the RFI, respondents were asked to address communication between NIH and the LGBTI research community. The RFI question had three parts: enhance understanding of the NIH mission; enhance understanding of the NIH funding and review processes; and, encourage individuals to compete for NIH funding.

Respondents made fewer comments about methods of enhancing communication than about the NIH activities from which content would be developed and then communicated. In regard to enhancing the understanding of the NIH mission, respondents identified the need for NIH to develop an LGBTI health research agenda and also to address funding opportunities that would support the research agenda. The need to include LGBTI researchers and advocates on study sections for LGBTI research proposals was identified. The recommendation for a dedicated NIH Office for LGBTI research and training was made.

In regard to understanding NIH funding and review processes, NIH was encouraged to use plain language and templates and to facilitate research partnerships with local health departments and community based organizations. NIH was also encouraged to review existing data, particularly success rates, to understand barriers and facilitators for LGBTI researchers.

The development of a community of LGBTI scholars through mentoring, training awards, and conferences was recommended as a way to encourage applications. Suggestions for improved outreach to potential applicants were put forward.

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Tabular Summary

NIH mission framework:	Fund, support, and conduct **extramural and intramural research**.
RCC Strategic Goals:	Reduce methodological or other challenges to data collection and analysis Create a **community** of researchers and scholars

Category (activity prompt)	Subcategory (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Enhance understanding of the NIH mission	Develop and communicate an LGBTI health research agenda	Many years ago, gay oriented foundations funded small meetings of 10 -30 for researchers to come together for a few days of talk ... NIMH funded two of these type meetings as well. One was the suicide meeting that launched the whole area of gay suicide concerns. A second brought together the few (at that time) funded NIH researchers to talk to NIMH staff about what they were doing in SO research--and I think this had the effect of making it much easier to successfully compete for NIH funding because staff witnessed the vitality of the area. The Office of Women's Health sponsored a large meeting on lesbian health that brought together both researchers and activists. These meetings are very good at pulling people together to understand where the science is at the moment and what needs to happen in the future. What isn't particularly useful are the 'how to apply for an NIH grant' sessions at conventions. These are too general and don't give NIH staff the opportunity to hear what is going on in the field.
		Inclusion of medical humanities, narrative medicine, medical anthropology, science and technology studies, and semiotics in to health research. These fields have a great deal to offer health-oriented research regarding transgender, gender variant, and gender-nonconforming populations, given the prevalence of dominant cultural beliefs that a person’s gender is determined by their anatomical sex, rather than being a complex social accomplishment that imparts particular meanings to the body.
		The IOM could form a multidisciplinary panel of experts that issues a report on the causes of all orientation and identity diversity. There is abundant peer-reviewed information showing that many biological factors, from genetic to epigenetics, from autosomal and sex chromosome related proteins (sry, dax, many others), gonadal hormone secretion, congenital adrenal hyperplasia, number of older brothers, maternal ingestion of of phenytoin or DPH or DES, that directly cause variations in genital anatomy, brain anatomy, fMRI changes, orientation, identity, physiological traits and capabilities (linguistic, visuospatial, throw to task, auditory, gait, phonation, EEG and others). The American public needs to know about this multidisciplinary information to help reduce discrimination and increase understanding about both orientation and

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		identity.
	Increase, target, or stabilize funding	Use Additional Career Development Tools. Consider Reconvening the Midcareer Minority Investigator Training. NIH should explore using existing tools for continued career development. NCI's Midcareer Minority Investigator Development Summit, convened some years ago, proved a very promising tool. We believe that model would work excellently for building the pipeline of successful researchers.
		Lobby for protected funding streams that will not make LGBTI-focused studies and policies subject to the political whims of any administration that might reverse LGBTI-supportive programs.
		NIH should establish an LGBTQ-specific post-doctoral fellowship opportunity, similar to the minority fellowship programs already geared towards minority racial and ethnic groups and people with disabilities.
	Improve peer review of LGBTI research proposals	Train, diversify, & monitor the peer review base. LGBTI research applicants have long bemoaned the uneven level of peer reviews of projects.
		Special funding reviews for this kind of research by folks that have ties in the communities you wish to reach.
	Provide oversight of LGBTI health research and training with a dedicated NIH Office	We need an office to oversee health disparities among LGBT populations that will help provide strategic guidance to ensure that the NIH supports the best possible science in this field. The office could ensure that investments are made in large national surveys to add sexual behavior, identity and attraction questions necessary to understanding which health disparities are most extreme for LGBT populations and which ones are the most dangerous for our communities. These data will provide crucial guidance as to where our intervention work should first begin for LGBT communities. The office could also look into whether additional investments might be made in existing NIH-funded projects to expand the scope of a given project to increase our understandings of health disparities in LGBT populations, much as we did with the investments that were made in HIV research among MSM. And finally, the office could advocate to ensure that training programs in LGBT health research are supported, to ensure that the next generation of researchers can build on the work already started in health disparities research in LGBT communities, and can begin the more difficult work of creating programs and approaches that will resolve the many dangerous health disparities that afflict LGBT communities.
Enhance understanding	Simplify the application	Create a simple to follow template to follow to request funding monies.

of the NIH funding and review processes	process	
	Encourage research partnerships	Encourage local health departments to partner with community and academe to educate and support NIH grant application and process.
	Understand barriers and facilitators for researchers based on review of NIH data	NIH must actively monitor the success rates of LGBTI research applicants versus non-LGBTI research applicants. We recommend that NIH institute a survey of applicant experiences, both funded and unfunded, paying special attention to the breakoff points for applicants who do not pursue funding.
Encourage individuals to compete for NIH funding	Develop a community of scholars through mentoring, training awards, meetings	There is basically no LGBTI research community other than AIDS researchers. You need to help build one.
		NIH could also play a more active role in the LGBTQ health research community by making an effort to educate and cultivate LGBTQ researchers. To start, NIH should create an LGBTQ advisory group of experts to assist with the development of LGBTQ studies and facilitate communication between NIH and the LGBTQ research community.
		Hold a national conference or planning meeting and invite the LGBTI research community; give grants and monies to those doing community based participatory research with the LGBTQ community. The communities/groups most affected by homophobia, transphobia, etc. should be the ones leading the research efforts.
		Foster Mentorship, preferably through LGBTI Centers of Excellence Mentorship opportunities must be developed. We recommend that NIH explore offering supplemental funding to existing mentorship structures.
		This research has the opportunity to directly engage the participation of LGBTI clinicians, patients, and families in evaluating the research proposal and in disseminating the research findings. Moreover, this research has the possibility of directly impacting the clinical education of future doctors and the short- and long-term clinical experiences of LGBTI patients and families.
	Improve outreach to potential applicants	Major disciplinary organizations/associations often have sub-groups of LGBTIQ members and/or members engaged in LGBTIQ health research. Listserv administrators would likely be happy to assist. Researchers in LGBTIQ health currently funded through the NIH could be contacted and asked to share with networks.
		Communication is most effective if funding is attached as the "carrot" so to speak. A prime communication device? May I suggest regional seminars with both the LGBTI

		research community and the various leadership people of the LGBTI private and grassroots organizations invited. LGBT people tend to be rather poor, so scholarships or stipends might help those in need to attend.
		The NIH Office of the Director could establish a time-limited ad hoc task force to develop options to enhance collaborations across federal agencies involved in the conduct, dissemination, and utilization of LGBTI research. The task force should include external stakeholders (researchers, academics, community partners, and advocates).
	Disseminate and communicate research findings	I think that NIH should work closely with health professions schools to engage with researchers and help them publicize their work among larger audiences. Additionally, I think the reports that NIH has released on LGBTQ health are a great start, but I'd love to see updates on the progress towards stated goals, and what is happening at a national level to further both research (RFPs, conferences, funding priorities, etc.) and advocacy (white papers, policy statements, etc.)
		Health Education Specialists (defined as one who has received a multi-disciplinary masters level (or beyond) education and who may possess specific certifications such as CHES/MCHES) are highly trained and ideally suited to incorporate emerging empirical understandings of these populations into individual practice and coordinate feedback channels among the NIH, researchers and clinical or community settings.
	Revise NIH websites and publications	Heightening visibility of LGBTI initiatives on NIHs website and vice versa.

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Section VI.D. NIH RFI Question about Outcome Indicators

NIH prompt

- NIH is requesting input [about] … **Outcome Indicators**…Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully.

Narrative Summary

Specific outcomes were advanced in response to this questions as well as methods for developing or identifying outcomes. Many of the specific outcomes recommended are standard NIH metrics; however, disaggregation by LGBTI investigators and topics, as recommended, is not standard and not well supported by existing RCDC or IC terms and codes nor by past or current applications and progress reports. The lack of common data elements and language for the LGBTI health research field in general and NIH databases will be problematic in defining and measuring outcome indicators. Moreover, many respondents adopted a broad approach to this question and recommended outcomes that are consistent with the federal public health and well-being mission but are beyond the mission of NIH.

Tabular Summary

NIH mission framework:	Fund, support, and conduct **extramural and intramural research**.
RCC Strategic Goal :	**Evaluate progress** on advancing SGM research health and well-being through NIH supported research and training.

Category (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)	Within NIH control?
Analyze applicant, application, and award data specific to LGBTI health issues	Increase in number of LGBTI-related grant applications submitted and number funded	Yes
	# reviewers on NIH panels who do LGBTIQ research (not necessarily NIH funded but research and publish on LGBTIQ health)	
	Increase in the amount of money NIH spends each year on projects/research that directly benefits the LGBT community	
Assess NIH outreach for LGBTI health research	# training events related to grant writing for target population	Yes
	Right now there is lack of clarity of when LGBTI populations are considered a health disparity population in NIH FOAs... Given the inclusion of LGBT groups in Healthy People 2020 and	

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	other federal disparity reports it is critical that LGBTI individuals are clearly recognized in health disparity FOAs. An outcome would be a review of FOAs to determine the clarity with which LGBTI individuals are included in the definition of health disparity populations.	
Analyze trends and status in the NIH LGBTI research agenda and conduct portfolio analyses of funded programs	An annual or bi-annual listening session for LGBTQ health research and policy stakeholders should be convened to review progress and make recommendations for continued improvements.	Yes
	Range of LGBTI projects by health topic area	
	Increased number of projects focused on LGBTQ populations and health issues that disproportionately impact LGBTQ communities	
Track the dissemination of LGBTI research findings	By monitoring media coverage and the use of certain key terms in social networking sites, NIH could verify if the information has saturated the community.	Yes
	Quarterly or yearly gathering of clinical researchers and their community partners to report on research being carried out	
	# papers published from funded grants [on LGBTI topics]	
Assess outcomes of NIH funded LGBTI career training and development awards	Some possible criteria for success might include: the inclusion of LGBTI relevant data within those materials used to train medical employees of all disciplines (including nurses and receptionists, who often receive little or no such training) and government employees; LGBTI information present alongside heterosexual information in materials for sexual education; a decline in the prevalence of and need for lists of "LGBT-friendly" doctors, therapists, etc.; more inclusive language in medical paperwork	Yes
Measure changes in LGBTI research methods	Inclusion of questions about one's sexual identity, orientation, and gender identity in national and population-level surveys	Yes
	Tracking number survey participants recruited through various [means]	
	For researchers conducting medical research on DSD, NIH could assess if and/or require that they include psychological outcomes among other DSD outcomes. Do they use culturally-competent language in recruitment? Do they allow individuals to self-label their identity on research materials? Though there is room for improvement, existing guidelines for counseling competencies, or self assessment tools for Systems of Care services (see SAMHSA) may be used to measure provider knowledge about DSD and related cultural competency. These tools could be used by the NIH to assess the quality of existing research/proposals and by researchers to assess the impact of interventions to expand awareness around DSD, starting with LGBT and medical research communities.	
Use a community-based approach	Creating definitions of well-being and wellness from the perspectives of LGBT	Yes

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to define LGBTI Research Outcomes	groups/populations	
	Look for ways of including members of the LGBTQI community (researchers and lay advocates) on assessment bodies. Be sure to include at least one member from the National Coalition for LGBT Health (or its successor organization) on assessment bodies.	
	Collaborative efforts with PCORI	
LGBTI Policy Outcomes	Apply all measures currently used for legal disparity populations to LGBTI populations	No
	The number of organizations/boards of certification requiring LGBTQI training	
LGBTI Health Services Outcomes	When you hear from doctors that folks are more open and asking for testing and information, you can know it is working	No
	More LGBTI people accessing health care	
LGBTI General Health Outcomes	Fewer health disparities	Partially
	Improved health outcomes	
	Improved mental health impacts	
LGBTI Specific Health Outcomes	Less cancer incidence	Partially
	Lower rates of STDs and reporting. When more folks come in with non-transmitted injuries for treatment, when over all rates of STDs show up in all segments of the population, when sex workers feel comfortable coming in to get treated, when talking about one's status is an accepted and expected part of pre-sex then you will know it is working.	
	Quantification of morbidities that might be harmed or helped by hormone regimens over time	
LGBTI Social, economic, and QOL outcomes	Higher numbers of LGBT people who can identify supportive resources	No
	Self-efficacy, self-reliance, life skills, independence, medication adherence, boundary-setting behaviors, harm reduction practices, healthcare seeking behavior, and personal outlook	
LGBTI Health Provider Outcomes	Physician (and other provider) attitudes, knowledge, comfort with transgender medicine	No
	Evaluating the cultural competency of U.S. medical schools in preparing their graduates to effectively work with LGBTI patients and families may yield not only significant data, but also opportunities to positively improve the ability of medical clinicians to meet patients’ and families’ needs.	

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Section VI.E. Transgender Health Research Listening Session

NIH prompts

- What are the top three priority areas in in need of research with respect to transgender health?
- What are the most limiting methodological barriers to research specific to transgender health?
- What areas of currently funded NIH research are best situated or most need to integrate transgender health research concerns?

Question answered but not asked (Induced prompt)

- What are the most limiting non-methodological barriers (regulatory, institutional, administrative)

Tabular Summary

RCC Strategic Goal	RCC Activity Prompt	Category (coded by analyst)	Representative Comment
Expand knowledge base	Priority areas for research	Gender transition and hormone use	
		Gender identity	
		Violence against transgender people	
		Behavioral and social science topics	
		Morbidity and disease Longitudinal studies of chronic illnesses	
		Health systems and health services	
	Integrate SGM research aims into existing programs and projects		HIV/AIDS research in sub-populations
			Patient registry for transgender and intersex care
Remove barriers	Limiting methodological barriers	Lack of epidemiologic & longitudinal data	
		Lack of measures	
		Lack of foundational research to support intervention research	

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	Limiting non-methodological barriers	Inability to disaggregate existing data by LGBTI populations	
		Lack of coordination across NIH	
		Insufficient NIH funding	
		Low cultural competency at NIH	

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Section VI.F. Program Staff Input Session

NIH prompt

- The facilitators solicited discussion with a line by line consideration of an early working draft of the SGM SP goals and objectives.

Invitees were sent five documents in advance: a working draft of the goals and objectives for the SGM SP, a report brief of the 2011 Institute of Medicine LGBT Health Report, the executive summary of an internal NIH document considering the IOM report and the NIH FY2010 LGBT Health Research Portfolio Analysis, a draft of the NIH FY 2012 LGBTI Health Research Portfolio Analysis, and a slide set on terminology related to SGM populations.

Section VI.G. NIH-Supported SGM Researchers Listening Session

NIH prompts

- What aspects of the NIH funding process are the most complicated for researchers interested in or actively working in SGM health research to navigate?
- What are some best practices that NIH can use to better support trainees interested in pursuing careers in SGMN health research, including types of scientific training?
- What are the NIH funding mechanisms/systems that are well suited to support SGM health research?
- What actions could NIH take to better support the career development of researchers (trainees and those beyond the trainee stage) in SGM health?
- What has been your experience with proposal review or participation on study sections?

Note: The Researchers Listening Session was embedded within the Program Staff Input Session. There is one narrative summary and one tabular summary (following) for both activities.

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Narrative Summary

The comments were coded to identify categories of interest to the RCC. Two main categories emerged, although other comments relvant to the RCC goals were made and are included in the Tabular Summary:

- Desirable characteristics of an NIH SGM Health Strategic Plan
  - The Plan should reflect the mission and goals of NIH in language and organization.
  - The Plan should recognize the roles, responsibilities, and authorities of NIH.
  - The Plan should recognize the roles, responsibilities, and authorities of individual NIH ICs.
  - The Plan should acknowledge distinctions between and among groups of stakeholders: NIH employees, persons working on behalf of NIH (reviewers), extramural scientists, SGM advocates as they relate to the Plan.
  - The Plan should be inclusive of SGM populations and subpopulations.
  - The Plan should be inclusive of multiple types and topics of research.

- Recommendations (strategies, actions, activities) to be considered for inclusion in the SGM Health Research Strategic Plan
  - Develop an SGM health and well-being research agenda
  - Develop a toolbox for researchers
  - Support study sections
  - Create an NIH Office on SGM Research
  - Employ and enhance existing NIH mechanisms and processes

Tabular Summary

RCC Strategic Goal	Category (coded by analyst)	Representative Comment
Expand the knowledge base	Foundational research data	In regard to the development of intervention-specific populations, researchers are in a Catch 22. They have to provide data to show the need to adapt interventions for specific populations. Do we fund multiple adaptations of an intervention for specific small populations?
		One of the challenges for review panels, and the IOM report is clear about this, is the limitations of existing data. The playing field does not even exist. The data often used to buttress research are not there or they are new. So this is a challenge to funding research.
Remove barriers	Terminology, methods, and measures	There is no current standard at HHS or other federal agencies for SGM terms.

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		There is a federal government, OMB, definition of minorities and under-represented groups and established policies exist, and these do go to reviewers, but SGM populations are not included in this definition or these policies.
Remove barriers	Workforce data regarding SGM populations and subpopulations	We have fairly clear ideas that certain groups are under-represented in the workforce, but we don't know this for SGM. Are they truly under-represented or has there been less self-identification because there has been no need or mechanism to identify?
		We want to establish whether SGM is under-represented in the scientific workforce.
		We can clearly articulate the value of diversity in the workforce. Is there data that we could collect to develop the rationale for inclusion as a minority?
Remove barriers	Competing research priorities within NIH	It's not that my IC will say that SGM research is not important; my IC will say, "Where's the data to support this proposal?" and "Why should we prioritize SGM issues over others that affect more people? "
		It will take a lot to convince some ICs that SGM is a priority area.
Create a community	Proposal development and submission by the extramural community	We need to work with SGM applicants to rethink Significance and Impact. Significance is not equal to Health. They should consider instead, "This research project has special significance in studying recruitment issues in a specific population." That is the innovativeness that researchers need to stress. Too many applicants fail to consult with Program Officers in a timely fashion.
		Program Officers have to help applicants learn to tailor proposals to IC interests.
		In regard to challenges of NIH funding, the point of connection for a potential applicant is easy or incredibly difficult depending upon the research topic of interest... The disease focus links researchers to specific ICs, but I have larger interests that could be relevant to LGBT… It is impossible to find a home, an IC, for research about health behaviors in a broad context.
		How can NIH encourage research in population-based samples? One challenge is in developing proposals targeted toward LGBT versus targeting LGBT as part of a larger population of interest.
Create a community	Proposal review	Few SGM researchers have served as reviewers for NIH. Not many know of the CSR Early Career Reviewer initiative.
		We need to get SGM experts on review panels who can educate their peers. This is the appropriate way to educate peer reviewers about the value of SGM research, rather than guidance from NIH staff.
		We can infuse peer review with SGM experts to educate one another, but we cannot mandate training for reviewers.
		We need a concerted campaign to get SGM researchers who identify as SGM to be on review

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		groups. SGM communities need to realize that they are the change agents.
Create a community	Institutional and collegial support for extramural SGM researchers	At the June 2013 listening session, some students reported that they felt isolated and that mentors could help overcome their isolation. The goal is to develop networks and better connections to reduce isolation and grow the cadre of researchers.
		Even experienced SGM researchers are perplexed by the career isolation that other researchers or potential researchers experience.
		We need to think about how to attract and engage people, how to convey the importance of SGM research in regard to biomedical science and the mission of NIH.
Create a community	Funding for career development and training in conducting SGM research	Training has been under-invested by NIH.
		I want an objective on funding: "Increase financial support for training in this area."
		There is a need for more SGM training.

Appendix D

Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations

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Notice Number: NOT-OD-13-076

Update: The following update relating to this announcement has been issued:

- October 24, 2013 - See Notice NOT-OD-14-011. Notice of Extension of the Response Date.

Key Dates

Release Date: June 27, 2013
Response Date: October 28, 2013 (Extended to **November 18, 2013** per NOT-OD-14-011)

Issued by

National Institutes of Health (NIH)

Purpose

This Notice is a time-sensitive Request for Information (RFI) inviting comments and suggestions on the health and health research needs, specific health issues and concerns for lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) populations.

Background

In 2009, the NIH commissioned the Institute of Medicine (IOM) Report to…assess the state of the science on the health status of…LGBT populations; identify research gaps and opportunities related to LGBT health; and outline a research agenda that will assist NIH in enhancing its research efforts in this area.

In March 2011, the IOM issued its report of this NIH commissioned study, The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding . In that same year, NIH leadership established the NIH LGBT Research Coordinating Committee, which consisted of representatives nominated by 21 Institutes, Centers, and Offices (ICOs).

The Committee conducted an analysis of the ongoing NIH research portfolio in LGBT health as a starting point for considering the IOM recommendations. By "mapping" the portfolio to the IOM recommendations, the Committee identified gaps and opportunities at the NIH. The Committee released its report and analysis "Consideration of the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals" in January 2013.

To continue to address this array of health issues and research opportunities, the Committee was reconstituted under the leadership of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

(NICHD) and the National Institute on Minority Health and Health Disparities (NIMHD). The new LGBTI Research Coordinating Committee serves as a trans-NIH committee to facilitate and coordinate collaborations and other activities related to LGBTI health across the NIH ICOs as well as with other HHS agencies. The NIH LGBTI Committee is an important forum for discussing the diverse health issues for these communities and serves as a catalyst for developing additional research and training initiatives to ensure that LGBTI health needs continue to be identified, addressed, and incorporated in our research and training initiatives, funding opportunities, and programs.

As part of its efforts to advance LGBTI health, NIH is requesting input through this Notice on the following issues to inform the development of an NIH LGBTI Research Strategic Plan:

Challenges (including, but not limited to):

- Methodological or other challenges to data collection and analysis for small and/or hard-to-reach and/or heterogeneous LGBTI populations, including the development of valid and reliable methods for asking individuals about their sexual orientation and gender identity to better understand and advance LGBTI health.

Opportunities (including, but not limited to):

- Opportunities to expand the knowledge base of LGBTI health (including those identified in the RCC report referenced above), existing data-collection efforts, and other resources and scientific advances on which further research could be built
- Training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency
- Effective ways to engage with the LGBTI health research and advocacy communities, which include the broad range of populations that may be encompassed by the term LGBTI, including, but not limited to:
  - People who identify as gay, lesbian, bisexual, or transgendered;
  - People with congenital “intersex” (disorders of sex development) conditions;
  - People who do not identify as LGBT, but nonetheless experience same-sex attraction and/or engage in same-sex sexual behaviors, which includes those who identify as queer and/or questioning; and
  - People whose gender identity differs from the sex assigned to them at birth; whose gender expression varies significantly from what is traditionally associated with or is typical for that group; and/or who vary from or reject for themselves traditional cultural conceptualizations of gender in terms of male-female dichotomy. This group includes people identify (or are identified) as transgendered, transsexual, cross-dressers, transvestites, two-spirit, queer, and/or questioning.
- Effective ways to enhance communication between the NIH and the LGBTI research community to enhance practical understanding of the NIH mission, as well as the NIH funding and review processes, and encourage individuals engaged in research and/or training in LGBTI health to compete for funding through various NIH mechanisms (both targeted and non-targeted to LGBTI health)

Outcome Indicators (including, but not limited to):

- Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully

Appendix D

Information Requested

To ensure a thorough and comprehensive consideration of these issues, responses are being sought from all stakeholders in the extramural community and the general public. Information is sought for each of the considerations identified above and any other issues that may affect NIH's efforts to address them.

Your comments may include but are not limited to:

1. Any of the areas identified above, those in the IOM LGBT report, those in the Committee's report, and any other specific areas you believe are worthy of consideration by the NIH LGBTI Committee, including identifying the critical issues(s) and impact(s) on LGBTI populations and health researchers.

2. Information about your personal or institutional experiences in these areas that you believe would be useful to the NIH LGBTI Committee in developing a strategic plan for LGBTI health research and advancing the health of LGBTI individuals.

Response to this RFI is voluntary. Responders are free to address any or all of the above items. Please note that the Government will not pay for response preparation or for the use of any information contained in the response. The comments collected will be analyzed and considered in planning and development of future initiatives. NIH will provide a summary of all input received that is responsive to this RFI.

All personal identifiers (e.g., names, addresses, email addresses, etc.) will be removed when responses are compiled. Please do not include any personally identifiable or confidential information that you do not wish to make public.

This RFI is for planning purposes only and is not a solicitation for applications or an obligation on the part of the United States (U.S.) Government to provide support for any ideas identified in response to it. No basis for claims against the U.S. Government shall arise as a result of a response to this request for information or from the Government's use of such information.

How to Submit a Response

All comments must be submitted electronically on the submission website.

Responses to this RFI will be accepted through October 28, 2013. You will see an electronic confirmation acknowledging receipt of your response, but will not receive individualized feedback on any suggestions.

Inquiries

Specific questions about this RFI should be directed to the following email address:
lgbtihealthresearch@od.nih.gov.

Appendix C

NIH REQUEST FOR INFORMATION: THE HEALTH AND HEALTH RESEARCH NEEDS, SPECIFIC HEALTH ISSUES AND CONCERNS FOR LESBIAN, GAY, BISEXUAL, TRANSGENDER, AND INTERSEX (LGBTI) POPULATIONS

September 2014

Summary of Comments

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Appendix C

Executive Summary

In 2009, the National Institutes of Health (NIH) commissioned the Institute of Medicine (IOM) to assess the state of the science on the health status of Lesbian, Gay, Bisexual, and Transgender (LGBT) populations, identify research gaps and opportunities related to LGBT health, and outline a research agenda that will assist NIH in enhancing its research efforts in this area. In March 2011, the IOM issued its report of this NIH commissioned study, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. In that same year, NIH leadership established the NIH LGBT Research Coordinating Committee, which consisted of representatives nominated by 21 Institutes, Centers, and Offices (ICOs).

The Committee conducted an analysis of the ongoing NIH research portfolio in LGBT health as a starting point for considering the IOM recommendations. By mapping the portfolio to the IOM recommendations, the Committee identified gaps and opportunities at the NIH. The Committee released its report and analysis "Consideration of the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals" in January 2013.

To continue to address this array of health issues and research opportunities, the Committee was reconstituted under the leadership of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the National Institute on Minority Health and Health Disparities (NIMHD). The Sexual and Gender Minority (SGM) Research Coordinating Committee (RCC) serves as a trans-NIH committee to facilitate and coordinate collaborations and other activities related to sexual and gender minority health, including lesbian, gay, bisexual, transgender, and intersex/differences or disorders of sex development (I/DSD)[1] (LGBTI) populations, across the NIH ICOs as well as with other Department of Health and Human Services (HHS) agencies. The NIH SGM RCC is an important forum for discussing the diverse health issues for these communities and serves as a catalyst for developing additional research and training initiatives to ensure that SGM health needs continue to be identified, addressed, and incorporated in our research and training initiatives, funding opportunities, and programs.

As part of its efforts to advance health research for these populations, NIH solicited input from the public through a Request for Information (RFI) to inform the development of an NIH Research Strategic Plan specific to sexual and gender minority health. For the purposes of this RFI, the term "LGBTI" was used to refer to all sexual and gender minority populations. This report provides a summary of the comments received in response to the RFI: "Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations" (NOT-OD-13-076). In this report, the terms "LGBTI" and "SGM" will be used interchangeably.

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[1] A separate RFI, published in 2013, solicited public suggestions for agenda items for a 2014 scientific workshop on differences/disorders of sex development (DSD, sometimes referred to as intersex), sponsored by NICHD, with additional support from the NIH Office of Research on Rare Disorders. A summary of responses to this RFI may be accessed at http://www.nichd.nih.gov/about/meetings/2014/Pages/032714.aspx.

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The RFI requested input on six issues:

1. Methodological or other challenges to data collection and analysis for small and/or heterogeneous LGBTI populations
2. Opportunities to expand the knowledge base of LGBTI health (including those identified in the portfolio analysis referenced above), existing data collection efforts, and other resources and scientific advances on which further research could be built
3. Training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency
4. Effective ways to engage with the LGBTI health research and advocacy communities, which include the broad range of populations that may be encompassed by the term LGBTI
5. Effective ways to enhance communication between the NIH and the LGBTI research community to enhance practical understanding of the NIH mission, as well as the NIH funding and review processes, and encourage individuals engaged in research and/or training in LGBTI health to compete for funding through various NIH mechanisms
6. Outcome Indicators – Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully.

NIH staff analyzed the 140 responses that were submitted by both individuals and organizations. In the case of an organizational response, often multiple people signed or otherwise endorsed the organizational response; however, the narrative statement was counted as one response. Sometimes general narrative statements were submitted rather than specific responses to the individual RFI questions. Overwhelmingly, the responses were aligned well with the recommendations from the IOM report, as well as input that NIH has received from previous solicitations from and interactions with the community.

Appendix C

Qualitative Analysis

Challenges to Data Collection

Responses

115 responses were submitted on the topic of identifying methodological or other challenges to data collection and analysis for small and/or heterogeneous LGBTI populations. Respondents included academic institutions (31 responses), non-profits/advocacy groups (44 responses), and private individuals (27 responses).

Overall, methodological challenges to data collection exist. Some solutions were proposed, including the addition of questions about sexual orientation/gender identity to all national-level surveys. LGBTI individuals may mistrust the research community, adding a further layer of complication to such efforts.

Summary

Barriers to Participation in Research

Respondents identified several barriers to participation in research studies and, therefore, adequate collection of LGBTI biomedical research data. One major challenge raised was the population of epidemiologic studies, including the burden of properly performing these studies. The impact of outside influences, such as bias, discrimination, politics, and tradition, was cited as a major reason for LGBTI individuals not being well represented in credible research protocols. Further, specific barriers to engaging LGBTI communities of color (due to perceptions of racism, discrimination, and exploitation), individuals in rural areas (who may be unconnected with any resources through which they can be identified), and the economically distressed (who may have work schedules that preclude participation in a study during regular clinic hours or who may lack Internet access needed to participate in an on-line survey) were identified. Because of such factors, there is often a lack of contact with and trust in the medical and research communities, respondents suggested that confidentiality concerns were another obstacle to LGBTI participation in biomedical research.

Validated Measures

It was suggested that validated measures for sampling the LGBTI population and sub-populations were needed. In particular, sub-population analyses are critical, as existing data from community samples suggest large differences among sub-groups. Further methodological research is needed to determine the benefits and drawbacks of various sampling methods (e.g., convenience samples, snowball samples, respondent driven samples, etc.). Absent this type of data, LGBTI focused grant proposals may be disadvantaged relative to studies of other populations, where validated sampling methods are established.

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Data and Terminology Standardization

Respondents emphasized the need for standardized terminology and definitions, as surveys often fail to accurately assess participants' sexuality and gender identity; this is particularly true for trans*[2] respondents, who are often a "hidden population" that seek anonymous outlets, such as the Internet, for guidance.

A number of respondents discussed the need for standardized data collection instruments that encompass the diversity of identity (e.g., a self-identified label of lesbian, gay, trans*, etc.), behavior (e.g., men who have sex with men [MSM]), and attraction (e.g., to whom one is emotionally and/or physically attracted irrespective of identity and behavior). Thus far, the majority of data collection instruments focus on identity, which has been helpful in identifying and clarifying LGBTI & Intersex/Disorders of Sex Development (I/DSD)-affected health disparities. However, research has shown differences in high-risk sexual practices and mental health between gay- or bisexually-identified MSM and heterosexually-identified MSM. This demonstrates the need for data collection instruments that make the distinction between identity and behavior. Respondents suggested that surveillance instruments should use the cognitively tested National Center for Health Statistics (NCHS) measure for sexual identity in conjunction with one of the recommended cognitively tested measures in the current paper by the Williams Institute Gender Identity in US Surveillance (GenIUSS) expert panel. Respondents also endorsed NIH support of collaboration among various data sources to standardize and harmonize data to facilitate research, and emphasized the need for registries and databases. The Center of Excellence for Transgender Health recently released guidelines for collecting data on trans* individuals and may serve as a useful resource.

Opportunities

Responses

There were 109 comments responsive to the topic of identifying opportunities to expand the knowledge base of LGBTI health, including existing data collection efforts and other resources and scientific advances on which further research could be built. Thirty (30) academic institutions, 41 non-profits/advocacy groups, and 25 private individuals provided responses.

A broad range of research was recommended. Long-term effects of hormone use among trans* and I/DSD populations was a major theme. Other prominent themes included life-course studies, mental health, and certain aspects of physical health, including tobacco and other substance abuse, obesity, and cancer. In general, individual responses tended to be from self-identified transpeople writing about trans* issues.

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[2] Refers to a diverse group of individuals who cross or transgress culturally defined categories of gender; see Definitions in Appendix

Appendix C

Summary

To address this question, several respondents proposed using a community-based participatory research (CBPR) approach, which is an avenue that could increase access to the LGBTI communities. Members could be engaged throughout the process, which may help to build trust and insure appropriate use of data. This may be particularly useful in reaching trans* communities and LGBTI communities of color as well.

National conferences, meetings, and workshops could provide an excellent opportunity to network, develop interdisciplinary collaborations, and promote research engagement.

Potential Federal Partners

A wide range of potential partners that may provide opportunities for collaboration were suggested, including other federal agencies. Furthering the addition of LGBTI data to existing national registries (NIAAA, SAMHSA, NCHS, and CDC) and creating a coherent point of access to these multiple registries was endorsed. Moreover, facilitating the process by which data elements are added to these registries may alleviate added burden.

Additional opportunities to develop formal collaborations with other HHS [e.g., Substance Abuse and Mental Health Services Administration (SAMSHA), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), and Agency for Health Research and Quality (AHRQ)] and non-HHS [e.g., National Endowment for the Humanities, Indian Health Services (IHS), and Veteran's Affairs (VA)] agencies in the areas of cultural competency and LGBTI training program development were mentioned. These collaborations may also establish new, effective, culturally competent, standards for data collection, and generate innovate research questions.

Potential Non-Federal Partners

Several other non-federal, professional organizations [e.g., American Psychological Association (APA), The American Counseling Association (ACA), The Endocrine Society (ES), and the International Consensus Conference on Intersex (ICCI)] have made initial efforts to increase cultural competency around I/DSD, and respondents encouraged NIH to work with these organizations to build upon these efforts. Respondents also emphasized the need for collaboration with advocacy and patient organizations whose primary focus is LGBTI health issues (e.g., Gay and Lesbian Medical Association, National Coalition for LGBT Health, and the Accord Alliance).

The establishment of cooperative education and internships were suggested as an important way to strengthen ties between higher education and local LGBTI clinics and community centers.

Promising international research projects on I/DSD populations may include opportunities for growth and collaboration. Such partnerships were suggested to be seized as a means to improve generalizability of research findings through inclusion of representative samples from across the globe.

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Training

Responses

One hundred (100) responses were submitted on the topic of ascertaining information on training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings – specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency. Respondents included academic institutions (24 responses), non-profit/advocacy groups (32 responses), and private individuals (24 responses).

Respondents interpreted this question in different ways, with some – mostly academic institutions – discussing the need for cultural competency within the review context (primarily, where it appears to be lacking), and individuals and advocacy groups calling for greater awareness of LGBTI issues within the clinical setting. Specific recommendations for physicians (e.g., “use the correct pronoun”) were offered.

Summary

This question was treated broadly by the respondents, and comments went beyond recommendations for NIH collaboration with other federal agencies to develop training. Often the responses served to confirm the importance of the topic raised or to validate the topic by personal experiences. Respondents identified specific groups of people who needed training, made suggestions about the content or curriculum of training, and suggested specific training models. Specifically, two different kinds of training were addressed: training for NIH researchers and potential NIH researchers about conducting SGM health research and more general training about SGM health for multiple groups, referred to as cultural competency. Most of the comments addressed the latter form of training. Respondents also addressed the narrow question of potential partners to NIH, including federal and other agencies and groups, who could both develop and deliver training.

Target Audiences

There was an emphasis on the need for training of health care providers, including medical students, physicians, nurses, psychologists, and others[3]. The need for provider training regarding multiple LGBTI populations, with an emphasis on trans* populations, was endorsed. Respondents also recommended training for NIH funded researchers and trainees through collaboration with professional associations that provide support for the various health disciplines.

Training Programs, Collaboration, and Curriculum

In regard to curriculum for cultural competency training, responses were numerous. Suggestions regarding the terms used to identify training programs (cultural competency versus cultural humility versus cultural awareness), as well as training in appropriate nomenclature for LGBTI populations and

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[3] Clinical training curricula are not generally within the scope of the NIH mission. For more information, please refer to the recently published AAMC publication entitled, *Curricular and Institutional Climate Changes to Improve Health Care for Individuals Who Are LGBT, Gender Noncomforming or Born with a DSD*

issues were made. A wide range of curriculum topics was also put forward, including standards of care, specific medical and behavioral conditions, societal issues, and provider interactions with patients and families. Training programs from the following federal agencies were mentioned: Substance Abuse and Mental Health Services Administration (SAMHSA), Health Resources and Services Administration (HRSA), HHS, and Administration for Children and Families (ACF). Boston University, the University of Central Florida, and the Fenway Summer Institute were mentioned as having model training programs.

Some of the agencies that were reported to have good training models (above) were also recommended as partners to develop and deliver training. Many other organizations were mentioned. A major addition in regard to partners was the need to include persons from LGBTI populations and persons from organizations serving LGBTI populations in development and delivery.

Finally, multiple respondents endorsed the need for evaluation of cultural competency training in regard to content, delivery, and outcomes.

NIH Mechanisms for Training

Respondents endorsed multiple NIH mechanisms that could support LGBTI research, including set-aside or other mechanisms for researchers addressing LGBTI health topics, mentoring, and loan repayment programs. Recommendations for administrative changes at NIH that support LGBTI training included the designation of LGBTI populations as disparities populations, the advancement of standardized terminology and definitions, the development of LGBTI leadership within NIH, and the creation of an NIH office dedicated to LGBTI health research.

Engagement

Responses

Eighty-eight (88) commenters responded to the topic of identifying effective ways to engage with the LGBTI health research and advocacy communities, which include the broad range of populations that may be encompassed by the term LGBTI. Twenty-three (23) academic institutions, 24 non-profits/advocacy groups, and 22 private individuals provided responses.

Respondents to this issue were passionate about engaging the NIH; several individual respondents offered to be interviewed or participate in a research study. Several researchers noted that the most effective way to engage with the research community would be to make funding available. Many others called for the designation of an individual or office within NIH that serves as the main point of contact for LGBTI/SGM-related activities.

Summary

In this section of the RFI, recommendations were made about how NIH could change policies, practices, and structures to locate more efficiently the communities, to be more welcoming toward the communities, and to engage more effectively with the communities. NIH staff were encouraged to demonstrate cultural competence and knowledge of LGBTI populations and health issues, particularly by changing terminology and demonstrating respect and support for LGBTI communities and advocates. NIH's use of the term transgendered in the RFI itself, rather than the term transgender or trans*, was raised, as this terminology is inconsistent with existing usage.

Collaboration with LGBTI Communities and Federal Agencies

Many respondents suggested that NIH could leverage resources by partnering with other organizations – both at the national and the community level. Specific groups and contact information, such as website address, were provided by some respondents. NIH was encouraged to support community-based participatory research (CBPR) and to include LGBTI experts in designing and reviewing research agendas and proposals. Recommendations about NIH collaborations with other federal, such as SAMHSA's Minority Fellowship Program (MFP), and non-federal agencies and programs were also put forward to increase engagement of those involved or interested in LGBTI research.

NIH Structure and Policies

Respondents recommended modifications to the administrative and programmatic structures at NIH to facilitate engagement with LGBTI communities. There was interest in an NIH office of LGBTI health, in establishing an LGBTI liaison at every IC, in convening meetings dedicated to LGBTI research, and in establishing an LGBTI research advisory group.

Several respondents endorsed the IOM recommendation with regard to including sexual and gender minorities in NIH-research, similar to the NIH policy on inclusion of women and minorities.

Communication

Responses

In this part of the RFI, respondents were asked to address communication between NIH and the LGBTI research community. There were 79 commenters responsive to the topic, which had three parts: enhance understanding of the NIH mission; enhance understanding of the NIH funding and review processes; and encourage individuals to compete for NIH funding. Respondents included academic institutions (23 responses), non-profits/advocacy groups (17 responses), and private individuals (24 responses).

Several of the responses called for transparency and rapid dissemination of research results.

Summary

Respondents made fewer comments about methods of enhancing communication than about the NIH activities from which content would be developed and then communicated.

Appendix C

NIH Mission

Respondents identified the need for NIH to develop an LGBTI health research agenda and also to address funding opportunities that would support the research agenda. The need to include LGBTI researchers and advocates on study sections for LGBTI research proposals was identified. The recommendation for a dedicated NIH Office for LGBTI research and training to enhance and facilitate communication was made.

NIH Funding and Review Processes

NIH was encouraged to use plain language and templates and to facilitate research partnerships with local health departments and community based organizations. NIH was also encouraged to review existing data, particularly success rates, to understand barriers and facilitators for LGBTI researchers.

Competition for NIH Funding

The development of a community of LGBTI scholars through mentoring, training awards, and conferences was recommended as a way to encourage applications. Suggestions for improved outreach to potential applicants were put forward.

Outcome Indicators

Responses

Sixty-one (61) responses were submitted on the topic of ascertaining information on outcome indicators, specifically potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully. Specific outcomes were advanced in response to this questions as well as methods for developing or identifying outcomes. Sixteen (16) academic institutions, 17 non-profits/advocacy groups, and 12 private individuals provided responses.

Responses focused on the need to monitor various metrics, including success rates and publications.

Summary

Many of the specific outcomes recommended are standard NIH metrics.

Data Collection and Evaluation

Respondents suggested that applicant, application, and award data specific to LGBTI health issues be collected and analyzed. Analysis of the portfolio of funded programs and the NIH LGBTI research agenda were suggested. NIH was encouraged to track the dissemination of LGBTI research findings, assess the outcomes of NIH funded LGBTI career training and development awards, and measure changes in LGBTI research methods.

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Current Barriers

Disaggregation by LGBTI investigators and topics, as recommended, is not standard and not well supported by existing RCDC or IC terms and codes, nor by past or current applications and progress reports. The lack of common data elements and language for the LGBTI health research field in general and NIH databases will be problematic in defining and measuring outcome indicators.

Recommendations Requiring Efforts Beyond the Mission of the NIH

Moreover, many respondents adopted a broad approach to this question and recommended outcomes that are consistent with the federal public health and well-being mission, but are far beyond the mission of NIH.

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Appendix

Analysis Tables

The comments in the tables below are taken directly from the responses received as a result of the RFI, and do not necessarily reflect the views of the NIH.

Challenges to Data Collection

NIH Mission Framework:	Fund, support, and conduct extramural and intramural research
RFI Request:	Methodological or other challenges to data collection and analysis for small and/or heterogeneous LGBTI populations

Category (coded by analyst)	Sub-category (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Populating studies (participant perspective)	Reluctance to self-identify	LGBTQI people can be reluctant to self-identify, particularly if there are doubts as to the safety of their anonymity, which can make data collection difficult. There are still plenty of people who are in real fear of their physical and emotional safety were their sexuality to be revealed.
	Inability to self-identify (Inappropriate or non-standard terminology)	Many of our transgender/gender-non-conforming/gender-fluid/gender queer clients report feeling uncomfortable when filling out paperwork at a doctor's office due to the lack of options when it comes to gender identity.
	Little access to research studies	An obvious challenge is that many people, especially in the transgender and intersex populations, are not public about their condition. In small towns, they may not have access to information or resources; they may also have limited access to the internet and therefore might not be able to participate in electronic surveys.
	Wariness about research participation	Recruitment becomes an issue when the local LGBTI communities perceive the research process as exploitative.
Populating studies (researcher perspective)	Sampling from populations of unknown distributions	Qualitative and ethnographic work that employs methods such as observational work and snowball or respondent driven sampling--methods that identify key informants who permit researchers to enter into hard to populations-- are needed to address the healthcare needs of this hidden population.
	Sampling from small populations	Knowing where to conduct recruitment without over-saturating the area (an urban concern); One of the challenges include a lack of adequate capacity to track these hard to reach populations.
	Locating potential subjects	Locating people in these categories can be a daunting task (especially transgender/transsexual/CD's [cross dressers],

		etc.) due to social taboos that often keep this community closed. They do not trust authorities and often attempt to "fly under the radar." This also means that it is difficult to determine if you have a representative sample of these groups.
	Inappropriate or non-standard terminology	Among researchers and the general public there is disagreement and misunderstanding around the parameters and definitions related to sexual orientation and gender identity; We need consistent and standardized questions for data collection that acknowledges and addresses sexual orientation, sexual behaviors, and gender identity.
Other methodological challenges	Little baseline epidemiology	We need to identify health indicators for LGBTQI people across generations, gender identities, cultures, race, and have a way to measure intersectionality. We need to collect qualitative data to better understand people's experiences and health indicators.
	Unknown interactions between research design and participant response	Community involvement in areas of concern and direction of research is vital.

Opportunities

NIH Mission Framework:	Fund, support, and conduct extramural and intramural research
RFI Request:	Opportunities to expand the knowledge base of LGBTI health…existing data collection efforts, and other resources and scientific advances on which further research could be built

Category (coded by analyst)	Sub-category (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Federal Research Partners	CDC	…work with NCHS to offer training at their data-users meeting. There are a large number of data-users who come and this will give them an opportunity to learn good approaches to using existing data; … work with the CDC and SAMHSA to harmonize their reports with the changes in our knowledge base.
	SAMHSA	SAMHSA's Minority Fellowship Program (MFP) has successfully engaged training programs, professional associations, and members of minority groups and could provide guidance to NIH on communication, outreach, and engagement to those involved or interested in LGBTI research. NIH could work with SAMSHA to encourage MFP grantees to identify researchers with interest in racial/ethnic minorities, engage LGBTI researchers of color and to include LGBTI in their cultural competency programming.
	Other Agencies	Recognizing multiple overlapping identities, NIH should partner

		with IHS, the VA, and other agencies who care for other populations that include LGBTI individuals whose individualized needs may not be met by generic studies of small populations of LGBTI people. NIH should advocate for HHS-wide policies to support LGBTI people, including CDC, HRSA, AHRQ, etc.
Non-Federal Research Partners	Professional Organizations	NIH should also reach out to relevant professional organizations (e.g. Div 44 of APA) through webinar or e-mail and provide guidance on the processes by which researchers conducting LGBTI research can apply for funding.
	Non-Profit Organizations	Partner with the non-profit foundations that serve this community (NCTE, NGLTF, Pride Foundation, etc.); Contacting and working with LGBTI organizations to provide education to these communities and disseminating information about needs for research and to obtain a pool of volunteers for research.
Research Areas of Opportunity	Community-Based Participatory Research (CBPR)	Increase investments in community-based participatory research (CBPR). CBPR is a collaborative approach to research that equitably involves all partners – researchers and subjects – in the study process. This collaborative process starts with the selection of a research topic that incorporates community input. This approach can be used to engage diverse sub-populations of LGBTI individuals and communities.
	Long-term effects of hormone	There is a need for increased research on the biological, neurological, and behavioral effects of hormone use (monitored and unmonitored) among transgender populations.
	Life-course studies	…expand the knowledge base of LGBTI health in the following areas: Promoting health and wellness of LGBTI individuals across the life-span; Increase studies of healthy aging in LGBTI populations (not just on an individual level, but as social networks grow thin and retirees move toward care-focused environments)
	Mental Health	The mental health challenges with surviving discrimination from family, society, religion, government, work etc. have only begun to be addressed.
	Physical Health	For so long, we have relied on HIV funding to look at the social determinants of health, but if there is money allocated to look at the social determinants of health outside of an HIV context that would truly be helpful to LGBTI communities.

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Training

NIH Mission Framework: Provide career development and training for researchers.
RFI Request: Training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency.

Category (coded by analyst)	Subcategory (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Groups needing training	Health care providers	Training of psychiatric/medical/psychological practitioners and researchers would have a ripple effect across LGBTQI communities and would transform the level and quality of care for the community. This should be a top NIH priority and should include integrated involvement from all members of the LGBTQI community with the support of academic and medical institutions. There is a grave and urgent need to train doctors in the all aspects of care for trans people which should include care for the entire lifecycle.
	Researchers	We urge the NIH to create a comprehensive research-training program that would raise awareness of LGBT health issues among researchers. Training the next generation of post-doctoral researchers to compete successfully for NIH grant funding provides the strongest opportunity to increase LGBTI research. Such a program could encourage researchers to include sexual and gender minorities explicitly in their samples, using the NIH policy on the inclusion of women and racial and ethnic minorities in clinical research as a model.
	Others	Diversity training specific to LGBTIQ needs to be mandatory for CPS, DCFS workers who deal with youth who have been made homeless by their LGBTIQ affiliations.
Curriculum suggestions		I would encourage NIH to shift the language away from "cultural competency" and adopt "cultural sensitivity" or "cultural humility." I would love to see NIH team up with CMS and mount a campaign to require all providers at hospitals or centers that receive Medicaid/Medicare funding to undergo a full two-day training that covers: 1. Cultural humility with LGBTQ patients 2. Challenging provider assumptions about patients' gender, sexuality, and behaviors in patient-provider interactions, especially in sexual history taking. 3. Asset-based approaches to LGBTQ health disparities (addressing homophobia and stigma and the reasons behind most disparities) 4. The important role of healthcare providers in the developmental stages of LGBTQ youth 5. National resources for providers (GLMA, HRC's Healthcare Equality Index, etc.)
		Investing in the training of health professionals may both facilitate the implementation of transgender health

		interventions and be an intervention itself. Funding initiatives to research the impact of providing future and current health professionals with transgender training, and training on the nature and impact of discrimination, might encourage health program academic accreditation bodies to institutionalize such training in health schools. Training of this nature should incorporate intersectionality, as well as principles of cultural humility, reflexivity, and transgender respect to create dialogue about partnering with marginalized individuals and communities.
Training models		SAMHSA has developed tools to promote cultural competency in behavioral health services providers. These tools include a resource kit on LGBTQ health issues and a brief aimed at educating policymakers, administrators and providers on providing services and supports for LGBTQ youth.
		Health Resources and Services Administration (HRSA) awarded $248,000 to create a National Training and Technical Assistance Center to help community health centers (CHCs) provide improved care for LGBTQ patients. The center will work with CHCs throughout the country to train health services professionals on working with LGBTQ populations.
Partners for developing and delivering curriculum		The NIH should not only collaborate with other federal agencies, but also with groups that provide guidance to clinical training programs, e.g. Association of American Medical Colleges, Association of Schools of Public Health, etc. to support the development of training curricula and to evaluate the progress of schools/programs towards an inclusive and welcoming environment for LGBTQ students, faculty, and staff.
		Partner with the non-profit foundations that serve this community (NCTE, NGLTF, Pride Foundation, etc.), academia and the professional organizations for the helping professions (NASW, APA, AMA, etc.). Encourage undergraduate and grad schools to offer courses and programs in LGBT studies (similar to Women's Studies).
NIH mechanisms that could support training and career development		Consult with LGBTI health care providers (there are a lot of organizations: Lyon-Martin Clinic, Mazonni Center, Callen-Lorde Clinic, GLMA, Rebellious Nurses, Transgender Health Initiatives, unaffiliated individuals, etc). Collaborate with LGBTI organizations (student, social, health, and community) to arrange competency trainings for providers working in clinical settings, these are very useful and low cost ways to develop cultural competency.
Policy, administrative, & personnel changes at NIH that would support training		Add LGBT as a disparity population and allow for postdoctoral funding opportunities in disparities to include LGBT issues.
		We need training grants at the graduate and post-doctoral levels in LGBT health research.
		We support extending the extramural loan repayment program

		to assist students who choose to study LGBT health issues within the context of graduate programs for Community Health Education.
		Offer grants, internships, fellowships, supervision and independent study at the NIH and partners for those who have recently earned their undergrad and graduate professional degrees who are seeking experience with the LGBT community.
Evaluation of NIH training and career development		The stark reality that we do not know what components constitute a successful cultural competency training program is an ongoing challenge. Adding to the difficulty, we do not know the effective individual or institutional dose, what outside supports are needed for institutional change, or what factors make some trainers more and less successful. All of these questions can be answered with research.
		Cultural competency of researchers and individuals working with LGBTI persons in clinical settings is necessary and ought to be ongoing. We identify three questions about cultural competency that could benefit from further attention: 1. Are scholarly perspectives from outside of medicine, for example sociologists and/or bioethicists, included in cultural competency training programs? 2. Are patient perspectives included in cultural competency training programs? If so, are all age groups represented? 3. How are cultural competency training programs assessed?
		Cultural competence training is repeatedly suggested as a valid way to change healthcare providers' attitudes and treatment of LGBT patients, but there is no data to suggest that this method is successful in achieving changes in provider-patient interactions. We need research on best practices. In the meantime, trainings are offered all over the country with simple pretest/posttest measures and these may be accomplishing nothing of value.

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Engagement

NIH Mission Framework:	Fund, support, and conduct extramural and intramural research.
RFI Request:	Effective ways to engage with the LGBTI health research and advocacy communities, which include the broad range of populations that may be encompassed by the term LGBTI.

Category (coded by analyst)	Subcategory (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Demonstrate cultural competence and knowledge of LGBTI populations and health issues	Change NIH terminology	I would recommend the medical researchers immediately drop the use of LGBTI and do not force people into association with that terminology. To do should be seen as a professional ethics violation. If you truly want the populations you will start from square one and use neutral terminology like same sex attracted and sex and gender diverse
		First – do not use the word "Transgendered" – it is inappropriate terminology. We are all gendered at birth – without our consent. But we don't say someone is "female-ed" or "male-ed" to identify their gender identity... nor should we say "transgender-ed" to identify the gender identity of persons who are transgender. The terminology will alienate people. It would be much more meaningful, and the dataset much more rich, and more reflecting of the actual community, if you looked beyond the binary construct. Many folks in the community identify as beyond the binary, non-binary etc. Indigenous people like myself who identify as Two Spirit do not fit neatly in these categories.
		Intersex persons are not by definition a particular orientation – as are lesbian and gay folk. There is a wide variation in expression for all intersex persons regardless of their particular genetic appellation. DSD is a genuine turn off for all intersex persons. We are not disorders. No matter how you dance around this subject, in the end, medical folk using DSD are unconsciously putting intersex folk in a "let's fix it" box.
		Careful classification is needed for a rigorous approach to this heterogeneous community. Specifically, transgender patients/gender identity patients can be divided into those who depend on medical intervention to achieve the desired gender and those who do not. The latter might be best be addressed by a welcoming, tolerant provider approach while the former require a knowledge set beyond tolerance. Although the categories often are divided along social lines, some barriers to care relate to treatment requirements. For example transgender and

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		intersex patients require access to good endocrine care and good surgical care that might not be needed for other gender/sexual minorities. As well, the risks/benefits of those interventions need to be assessed independently.
	Demonstrate respect and support	The NIH should promote the development of a culture, infrastructure, and processes that work towards closing the gap in care that currently exists for the LGBT and DSD-affected populations. For example, we strongly encourage the NIH to include cultural sensitivity material as part of the Responsible Conduct of Research training required of NIH-funded researchers. Such national requirements will support the development of institutional climates welcoming of diversity, including LGBT and DSD affected individuals
		These populations need to feel that they are safe to discuss and be open about their identity in public health organizations or they will be ineffective with data collection relating to their specific issues. Creating safe zones at all public health organizations will increase the reliability of this population to express themselves in a way that effectively genuinely honestly depicts their actual health needs.
Collaborate & interact with target populations	Support community-based participatory research	Utilize Participatory Action Research/Community Based Participatory Research to engage various LGBT communities in the struggle to enhance their health and well-being. Ask the communities what they think are the issues that most impact their health and well-being and truly partner with them in addressing what can be addressed.
		Increase investments in community-based participatory research (CBPR). CBPR is a collaborative approach to research that equitably involves all partners – researchers and subjects – in the study process. This collaborative process starts with the selection of a research topic that incorporates community input. This approach can be used to engage diverse sub-populations of LGBTI individuals and communities.
	Reach out to specific populations and groups	You need to approach LGBT advocacy organizations - local, state and national (not just national ones) - and seek anonymous input from their members.
		We recommend continuing to reach out for community input to experts through listening sessions and presenting at community gatherings and at student mentorship events.
		We believe that marginalized populations mentioned above may often times be utilizing resources at clinics,

		non-profit organizations, and community centers. Connection to such institutions is necessary to engage with LGBTI persons in regards to health research.
		Use CTSAs for community engagement (but not exclusively)
Modify NIH administrative and programmatic structures		Establish an LGBTI research advisory body to regularly engage external stakeholders
		Establish an office of LGBTI health
		Nourishing a strong cadre of openly LGBTI leaders at NIH is the single best strategy for ensuring information channels are easily accessible to outside experts. We recommend appointing an LGBTI liaison at every Institute. Initiatives are helpful, but, especially at NIH, information is transmitted via personal connections, and larger communication initiatives can't replace the value of having an openly LGBTI liaison at every Institute.
		There is currently no address at NIH for transgender related research. The current PA advocates for research in the existing categories for NIH that might have impact on transgender individuals. An approach that examines transgender health care more broadly would be cross discipline currently and might seem to be part of the mission of any institute. NIH should designate a specific home for transgender (and perhaps also intersex) research in order to encourage individuals engaged in research to submit transgender oriented proposals.
Modify NIH policy to mandate inclusion of LGBTI populations and data in clinical research		We understand that the overall health and wellness of the LGBTQI population is impacted over the life course by a wide array of issues. By widely implementing the IOM's recommendations mandating the inclusion of LGBTQI people and LGBTQI data in all studies (or justifying their exclusion), the NIH can see that this depth of research is achieved.
Update NIH and sister agency reports with contemporary LGBTI research data		One of the continuing disappointments is that researchers provide information and new knowledge but that doesn't seem to update federal reports. This is an opportunity for NIH to work with the CDC and SAMHSA to harmonize their reports with the changes in our knowledge base.
Collaborate with non-research organizations		The National Endowment for the Arts, National Endowment for the Humanities, and NIH should collaborate to integrate humanistic and cultural intervention as a way to not only enhance cultural competence but deepen cultural awareness, humility, and understanding for scientists and support staff affiliated with those institutions.
Advocate for federal		Spend much more time talking about the duty and

policy changes		obligation of the United States government to outlaw discrimination based on sexual orientation and gender identity to create a safe environment for our development and lives.

Communication

NIH Mission Framework:	Fund, support, and conduct extramural and intramural research.
RFI Request:	Effective ways to enhance communication between the NIH and the LGBTI research community to enhance practical understanding of the NIH mission, as well as the NIH funding and review processes, and encourage individuals engaged in research and/or training in LGBTI health to compete for funding through various NIH mechanisms (both targeted and non-targeted to LGBTI health.

Category (activity prompt)	Subcategory (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Enhance understanding of the NIH mission	Develop and communicate an LGBTI health research agenda	Many years ago, gay oriented foundations funded small meetings of 10 -30 for researchers to come together for a few days of talk ... NIMH funded two of these type meetings as well. One was the suicide meeting that launched the whole area of gay suicide concerns. A second brought together the few (at that time) funded NIH researchers to talk to NIMH staff about what they were doing in SO research--and I think this had the effect of making it much easier to successfully compete for NIH funding because staff witnessed the vitality of the area. The Office of Women's Health sponsored a large meeting on lesbian health that brought together both researchers and activists. These meetings are very good at pulling people together to understand where the science is at the moment and what needs to happen in the future. What isn't particularly useful are the 'how to apply for an NIH grant' sessions at conventions. These are too general and don't give NIH staff the opportunity to hear what is going on in the field.
		Inclusion of medical humanities, narrative medicine, medical anthropology, science and technology studies, and semiotics in to health research. These fields have a great deal to offer health-oriented research regarding transgender, gender variant, and gender-nonconforming populations, given the prevalence of dominant cultural beliefs that a person’s gender is determined by their anatomical sex, rather than being a complex social accomplishment that imparts particular meanings to the body.
		The IOM could form a multidisciplinary panel of experts

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		that issues a report on the causes of all orientation and identity diversity. There is abundant peer-reviewed information showing that many biological factors, from genetic to epigenetics, from autosomal and sex chromosome related proteins (sry, dax, many others), gonadal hormone secretion, congenital adrenal hyperplasia, number of older brothers, maternal ingestion of phenytoin or DPH or DES, that directly cause variations in genital anatomy, brain anatomy, fMRI changes, orientation, identity, physiological traits and capabilities (linguistic, visuospatial, throw to task, auditory, gait, phonation, EEG and others). The American public needs to know about this multidisciplinary information to help reduce discrimination and increase understanding about both orientation and identity.
	Increase, target, or stabilize funding	Use Additional Career Development Tools. Consider Reconvening the Midcareer Minority Investigator Training. NIH should explore using existing tools for continued career development. NCI's Midcareer Minority Investigator Development Summit, convened some years ago, proved a very promising tool. We believe that model would work excellently for building the pipeline of successful researchers.
		Lobby for protected funding streams that will not make LGBTI-focused studies and policies subject to the political whims of any administration that might reverse LGBTI-supportive programs.
		NIH should establish an LGBTQ-specific post-doctoral fellowship opportunity, similar to the minority fellowship programs already geared towards minority racial and ethnic groups and people with disabilities.
	Improve peer review of LGBTI research proposals	Train, diversify, & monitor the peer review base. LGBTI research applicants have long bemoaned the uneven level of peer reviews of projects.
		Special funding reviews for this kind of research by folks that have ties in the communities you wish to reach.

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	Provide oversight of LGBTI health research and training with a dedicated NIH Office	We need an office to oversee health disparities among LGBT populations that will help provide strategic guidance to ensure that the NIH supports the best possible science in this field. The office could ensure that investments are made in large national surveys to add sexual behavior, identity and attraction questions necessary to understanding which health disparities are most extreme for LGBT populations and which ones are the most dangerous for our communities. These data will provide crucial guidance as to where our intervention work should first begin for LGBT communities. The office could also look into whether additional investments might be made in existing NIH-funded projects to expand the scope of a given project to increase our understandings of health disparities in LGBT populations, much as we did with the investments that were made in HIV research among MSM. And finally, the office could advocate to ensure that training programs in LGBT health research are supported, to ensure that the next generation of researchers can build on the work already started in health disparities research in LGBT communities, and can begin the more difficult work of creating programs and approaches that will resolve the many dangerous health disparities that afflict LGBT communities.
Enhance understanding of the NIH funding and review processes	Simplify the application process	Create a simple to follow template to follow to request funding monies.
	Encourage research partnerships	Encourage local health departments to partner with community and academe to educate and support NIH grant application and process.
	Understand barriers and facilitators for researchers based on review of NIH data	NIH must actively monitor the success rates of LGBTI research applicants versus non-LGBTI research applicants. We recommend that NIH institute a survey of applicant experiences, both funded and unfunded, paying special attention to the breakoff points for applicants who do not pursue funding.
Encourage individuals to compete for NIH funding	Develop a community of scholars through mentoring, training awards, meetings	There is basically no LGBTI research community other than AIDS researchers. You need to help build one.
		NIH could also play a more active role in the LGBTQ health research community by making an effort to educate and cultivate LGBTQ researchers. To start, NIH should create an LGBTQ advisory group of experts to assist with the development of LGBTQ studies and facilitate communication between NIH and the LGBTQ research community.

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		Hold a national conference or planning meeting and invite the LGBTI research community; give grants and monies to those doing community based participatory research with the LGBTQ community. The communities/groups most affected by homophobia, transphobia, etc. should be the ones leading the research efforts.
		Foster Mentorship, preferably through LGBTI Centers of Excellence Mentorship opportunities must be developed. We recommend that NIH explore offering supplemental funding to existing mentorship structures.
		This research has the opportunity to directly engage the participation of LGBTI clinicians, patients, and families in evaluating the research proposal and in disseminating the research findings. Moreover, this research has the possibility of directly impacting the clinical education of future doctors and the short- and long-term clinical experiences of LGBTI patients and families.
	Improve outreach to potential applicants	Major disciplinary organizations/associations often have sub-groups of LGBTIQ members and/or members engaged in LGBTIQ health research. Listserv administrators would likely be happy to assist. Researchers in LGBTIQ health currently funded through the NIH could be contacted and asked to share with networks.
		Communication is most effective if funding is attached as the "carrot" so to speak. A prime communication device? May I suggest regional seminars with both the LGBTI research community and the various leadership people of the LGBTI private and grassroots organizations invited. LGBT people tend to be rather poor, so scholarships or stipends might help those in need to attend.
		The NIH Office of the Director could establish a time-limited ad hoc task force to develop options to enhance collaborations across federal agencies involved in the conduct, dissemination, and utilization of LGBTI research. The task force should include external stakeholders (researchers, academics, community partners, and advocates).
	Disseminate and communicate research findings	I think that NIH should work closely with health professions schools to engage with researchers and help them publicize their work among larger audiences. Additionally, I think the reports that NIH has released on LGBTQ health are a great start, but I'd love to see updates on the progress towards stated goals, and what is happening at a national level to further both research (RFPs, conferences, funding priorities, etc.) and advocacy (white papers, policy statements, etc.)
		Health Education Specialists (defined as one who has

		received a multi-disciplinary masters level (or beyond) education and who may possess specific certifications such as CHES/MCHES) are highly trained and ideally suited to incorporate emerging empirical understandings of these populations into individual practice and coordinate feedback channels among the NIH, researchers and clinical or community settings.
	Revise NIH websites and publications	Heightening visibility of LGBTI initiatives on NIHs website and vice versa.

Outcome Indicators

NIH Mission Framework:	Fund, support, and conduct extramural and intramural research.
RFI Request:	Outcome Indicators – Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully.

Category (coded by analyst)	Selected comment(s) (may be explanatory, representative, or unique)
Analyze applicant, application, and award data specific to LGBTI health issues	Increase in number of LGBTI-related grant applications submitted and number funded
	# reviewers on NIH panels who do LGBTIQ research (not necessarily NIH funded but research and publish on LGBTIQ health)
	Increase in the amount of money NIH spends each year on projects/research that directly benefits the LGBT community
Assess NIH outreach for LGBTI health research	# training events related to grant writing for target population
	Right now there is lack of clarity of when LGBTI populations are considered a health disparity population in NIH FOAs... Given the inclusion of LGBT groups in Healthy People 2020 and other federal disparity reports it is critical that LGBTI individuals are clearly recognized in health disparity FOAs. An outcome would be a review of FOAs to determine the clarity with which LGBTI individuals are included in the definition of health disparity populations.
Analyze trends and status in the NIH LGBTI research agenda and conduct portfolio analyses of funded programs	An annual or bi-annual listening session for LGBTQ health research and policy stakeholders should be convened to review progress and make recommendations for continued improvements.
	Range of LGBTI projects by health topic area
	Increased number of projects focused on LGBTQ populations and health issues that disproportionately impact LGBTQ communities
Track the dissemination of LGBTI research findings	By monitoring media coverage and the use of certain key terms in social networking sites, NIH could verify if the information has saturated the community.
	Quarterly or yearly gathering of clinical researchers and their community partners to report on research being carried out
	# papers published from funded grants [on LGBTI topics]
Assess outcomes of NIH	Some possible criteria for success might include: the inclusion of LGBTI

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funded LGBTI career training and development awards	relevant data within those materials used to train medical employees of all disciplines (including nurses and receptionists, who often receive little or no such training) and government employees; LGBTI information present alongside heterosexual information in materials for sexual education; a decline in the prevalence of and need for lists of "LGBT-friendly" doctors, therapists, etc.; more inclusive language in medical paperwork
Measure changes in LGBTI research methods	Inclusion of questions about one's sexual identity, orientation, and gender identity in national and population-level surveys
	Tracking number survey participants recruited through various [means]
	For researchers conducting medical research on DSD, NIH could assess if and/or require that they include psychological outcomes among other DSD outcomes. Do they use culturally-competent language in recruitment? Do they allow individuals to self-label their identity on research materials? Though there is room for improvement, existing guidelines for counseling competencies, or self-assessment tools for Systems of Care services (see SAMHSA) may be used to measure provider knowledge about DSD and related cultural competency. These tools could be used by the NIH to assess the quality of existing research/proposals and by researchers to assess the impact of interventions to expand awareness around DSD, starting with LGBT and medical research communities.
Use a community-based approach to define LGBTI Research Outcomes	Creating definitions of well-being and wellness from the perspectives of LGBT groups/populations
	Look for ways of including members of the LGBTQI community (researchers and lay advocates) on assessment bodies. Be sure to include at least one member from the National Coalition for LGBT Health (or its successor organization) on assessment bodies.
	Collaborative efforts with PCORI
LGBTI Policy Outcomes	Apply all measures currently used for legal disparity populations to LGBTI populations
	The number of organizations/boards of certification requiring LGBTQI training
LGBTI Health Services Outcomes	When you hear from doctors that folks are more open and asking for testing and information, you can know it is working
	More LGBTI people accessing health care
LGBTI General Health Outcomes	Fewer health disparities
	Improved health outcomes
	Improved mental health impacts
LGBTI Specific Health Outcomes	Less cancer incidence
	Lower rates of STDs and reporting. When more folks come in with non-transmitted injuries for treatment, when overall rates of STDs show up in all segments of the population, when sex workers feel comfortable coming in to get treated, when talking about one's status is an accepted and expected part of pre-sex then you will know it is working.
	Quantification of morbidities that might be harmed or helped by hormone regimens over time

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LGBTI Social, Economic, and QOL outcomes	Higher numbers of LGBT people who can identify supportive resources
	Self-efficacy, self-reliance, life skills, independence, medication adherence, boundary-setting behaviors, harm reduction practices, healthcare seeking behavior, and personal outlook
LGBTI Health Provider Outcomes	Physician (and other provider) attitudes, knowledge, comfort with transgender medicine
	Evaluating the cultural competency of U.S. medical schools in preparing their graduates to effectively work with LGBTI patients and families may yield not only significant data, but also opportunities to positively improve the ability of medical clinicians to meet patients’ and families’ needs.

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Definitions

Bisexual[4] – One whose sexual or romantic attractions and behaviors are directed at members of both sexes to a significant degree

Gay[4] – An attraction and/or behavior focused exclusively or mainly on members of the same sex or gender identity; a personal or social identity based on one's same-sex attractions and membership in a sexual-minority community

Gender[4] – Denotes the cultural meanings of patterns of behavior, experience, and personality that are labeled as masculine or feminine

Gender Expression[4] – Denotes the manifestation of characteristics in one's personality, appearance, and behavior that are culturally defined as masculine or feminine

Gender Identity[4] – Generally refers to a person's basic sense of being a man or a boy, or a woman or a girl; gender identity can be congruent/incongruent with one's sex assigned at birth

Heterosexual[4] – Refers to individuals who identify as "heterosexual" or "straight" or whose sexual or romantic attractions and behaviors focus exclusively or mainly on members of the other sex or gender identity

Homosexual[4] – As an adjective, used to refer to same-sex attraction, sexual behavior, or sexual orientation identity; as a noun, used as an identity label by some persons whose sexual attractions and behaviors are exclusively or mainly directed to people of their same sex

Intersectionality[4] – encompasses a set of foundational claims and organizing principles for understanding social inequality and its relationship to individuals' marginalized status based on such dimensions as race, ethnicity, and social class

Intersex/Differences or Disorders of Sex Development[5] – Refers to individuals with atypical reproductive development, which results in chromosomal, gonadal, and/or anatomic sex that varies from typical development and that commonly presents at birth; atypical gender-role behavior is more common in children with these conditions, but developmental determinants of gender identity and/or sexual orientation are not well understood

Lesbian[4] – As an adjective, used to refer to female same-sex attraction and sexual behavior; as a noun, used as a sexual orientation identity label by women whose sexual attractions and behaviors are exclusively or mainly directed to other women

MSM – Males who have sex with males, but do not necessarily identify as gay or bisexual

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[4] Institute of Medicine. *Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. The National Academies Press, 2011.

[5] Lee, P.A., C.P. Houk, S.F. Ahmed, and I.A. Hughes. Consensus statement on management of intersex disorders. *Pediatrics*. 2006, 118(2):e488-500.

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Queer[4] – In contemporary usage, an inclusive, unifying sociopolitical, self-affirming umbrella term for people who are gay, lesbian, bisexual, pan- sexual, transgender, transsexual, intersexual/DSD, genderqueer, or of any other non-heterosexual sexuality, sexual anatomy, or gender identity. Historically, a term of derision for gay, lesbian, and bisexual people

Sex[4] – Biological construct, referring to the genetic, hormonal, anatomical, and physiological characteristics on whose basis one is labeled at birth as either male or female

Sexual and/or Gender Minority – People whose sexual orientations and/or gender identities/expressions, or reproductive development vary from traditional, societal, and/or cultural norms; encompasses populations included in the acronym LGBTI (lesbian, gay, bisexual, transgender, and intersex) and those whose sexual orientation and/or gender identity varies, or may not self-identify as LGBTI

Sexual Orientation[4] – An enduring pattern of or disposition to experience sexual or romantic desires for, and relationships with, people of one's same sex (Lesbian or Gay), the other sex (Straight), or both sexes (Bisexual)

Stigma[4] – The inferior status, negative regard, and relative powerlessness that society collectively assigns to individuals and groups that are associated with various conditions, statuses, and attributes

Trans* (with the asterisk) – Refers to a diverse group of individuals who cross or transgress culturally defined categories of gender; the term may be used interchangeably with transgender

Transgender[4] – Refers to a diverse group of people who cross or transcend culturally defined categories of gender; increasingly used to encompass a family of gender-variant identities and expressions, but opinions of the term may vary by individual or geographic reason or, in the case of Two Spirit (see below), by tribe

Transsexual[4] – An individual who strongly identifies with the other sex and seeks hormones and/or sex reassignment surgery to feminize or masculinize the body; may live full time in the cross-gender role

Two Spirit[4] – Adopted in 1990 at the third annual spiritual gathering of GLBT Natives, the term derives from the northern Algonquin word *niizh manitoag*, meaning "two spirits," and refers to the inclusion of both feminine and masculine components in one individual[6]

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[6] Anguksuar, L. R. 1997. A postcolonial perspective on western [mis]conceptions of the cosmos and the restoration of indigenous taxonomies. In *Two-spirit people: Native American gender identity, sexuality, and spirituality*, edited by S.E. Jacobs, W. Thomas, and S. Lang. Chicago, IL: University of Illinois Press. Pp. 217–222.

Appendix C

Request for Information

Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations

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Notice Number: NOT-OD-13-076

Update: The following update relating to this announcement has been issued:

- October 24, 2013 - See Notice NOT-OD-14-011. Notice of Extension of the Response Date.

Key Dates

Release Date: June 27, 2013
Response Date: October 28, 2013 (Extended to **November 18, 2013** per NOT-OD-14-011)

Issued by

National Institutes of Health (NIH)

Purpose

This Notice is a time-sensitive Request for Information (RFI) inviting comments and suggestions on the health and health research needs, specific health issues and concerns for lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) populations.

Background

In 2009, the NIH commissioned the Institute of Medicine (IOM) Report to…assess the state of the science on the health status of…LGBT populations; identify research gaps and opportunities related to LGBT health; and outline a research agenda that will assist NIH in enhancing its research efforts in this area.

In March 2011, the IOM issued its report of this NIH commissioned study, The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding . In that same year, NIH leadership established the NIH LGBT Research Coordinating Committee, which consisted of representatives nominated by 21 Institutes, Centers, and Offices (ICOs).

The Committee conducted an analysis of the ongoing NIH research portfolio in LGBT health as a starting point for considering the IOM recommendations. By “mapping” the portfolio to the IOM recommendations, the Committee identified gaps and opportunities at the NIH. The Committee released its report and analysis “Consideration of the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals” in January 2013.

Appendix C

To continue to address this array of health issues and research opportunities, the Committee was reconstituted under the leadership of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the National Institute on Minority Health and Health Disparities (NIMHD). The new LGBTI Research Coordinating Committee serves as a trans-NIH committee to facilitate and coordinate collaborations and other activities related to LGBTI health across the NIH ICOs as well as with other HHS agencies. The NIH LGBTI Committee is an important forum for discussing the diverse health issues for these communities and serves as a catalyst for developing additional research and training initiatives to ensure that LGBTI health needs continue to be identified, addressed, and incorporated in our research and training initiatives, funding opportunities, and programs.

As part of its efforts to advance LGBTI health, NIH is requesting input through this Notice on the following issues to inform the development of an NIH LGBTI Research Strategic Plan:

Challenges (including, but not limited to):

- Methodological or other challenges to data collection and analysis for small and/or hard-to-reach and/or heterogeneous LGBTI populations, including the development of valid and reliable methods for asking individuals about their sexual orientation and gender identity to better understand and advance LGBTI health.

Opportunities (including, but not limited to):

- Opportunities to expand the knowledge base of LGBTI health (including those identified in the RCC report referenced above), existing data-collection efforts, and other resources and scientific advances on which further research could be built
- Training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency
- Effective ways to engage with the LGBTI health research and advocacy communities, which include the broad range of populations that may be encompassed by the term LGBTI, including, but not limited to:
    - People who identify as gay, lesbian, bisexual, or transgendered;
    - People with congenital “intersex” (disorders of sex development) conditions;
    - People who do not identify as LGBT, but nonetheless experience same-sex attraction and/or engage in same-sex sexual behaviors, which includes those who identify as queer and/or questioning; and
    - People whose gender identity differs from the sex assigned to them at birth; whose gender expression varies significantly from what is traditionally associated with or is typical for that group; and/or who vary from or reject for themselves traditional cultural conceptualizations of gender in terms of male-female dichotomy. This group includes people identify (or are identified) as transgendered, transsexual, cross-dressers, transvestites, two-spirit, queer, and/or questioning.
- Effective ways to enhance communication between the NIH and the LGBTI research community to enhance practical understanding of the NIH mission, as well as the NIH funding and review processes, and encourage individuals engaged in research and/or training in LGBTI health to compete for funding through various NIH mechanisms (both targeted and non-targeted to LGBTI health)

Outcome Indicators (including, but not limited to):

- Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully

Appendix C

Information Requested

To ensure a thorough and comprehensive consideration of these issues, responses are being sought from all stakeholders in the extramural community and the general public. Information is sought for each of the considerations identified above and any other issues that may affect NIH's efforts to address them.

Your comments may include but are not limited to:

1. Any of the areas identified above, those in the IOM LGBT report, those in the Committee's report, and any other specific areas you believe are worthy of consideration by the NIH LGBTI Committee, including identifying the critical issues(s) and impact(s) on LGBTI populations and health researchers.

2. Information about your personal or institutional experiences in these areas that you believe would be useful to the NIH LGBTI Committee in developing a strategic plan for LGBTI health research and advancing the health of LGBTI individuals.

Response to this RFI is voluntary. Responders are free to address any or all of the above items. Please note that the Government will not pay for response preparation or for the use of any information contained in the response. The comments collected will be analyzed and considered in planning and development of future initiatives. NIH will provide a summary of all input received that is responsive to this RFI.

All personal identifiers (e.g., names, addresses, email addresses, etc.) will be removed when responses are compiled. Please do not include any personally identifiable or confidential information that you do not wish to make public.

This RFI is for planning purposes only and is not a solicitation for applications or an obligation on the part of the United States (U.S.) Government to provide support for any ideas identified in response to it. No basis for claims against the U.S. Government shall arise as a result of a response to this request for information or from the Government's use of such information.

How to Submit a Response

All comments must be submitted electronically on the submission website.

Responses to this RFI will be accepted through October 28, 2013. You will see an electronic confirmation acknowledging receipt of your response, but will not receive individualized feedback on any suggestions.

Inquiries

Specific questions about this RFI should be directed to the following email address:
lgbtihealthresearch@od.nih.gov.

Appendix D

Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations

Notice Number: NOT-OD-13-076

Update: The following update relating to this announcement has been issued:

- October 24, 2013 - See Notice NOT-OD-14-011. Notice of Extension of the Response Date.

Key Dates

Release Date: June 27, 2013
Response Date: October 28, 2013 (Extended to **November 18, 2013** per NOT-OD-14-011)

Issued by

National Institutes of Health (NIH)

Purpose

This Notice is a time-sensitive Request for Information (RFI) inviting comments and suggestions on the health and health research needs, specific health issues and concerns for lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) populations.

Background

In 2009, the NIH commissioned the Institute of Medicine (IOM) Report to…assess the state of the science on the health status of…LGBT populations; identify research gaps and opportunities related to LGBT health; and outline a research agenda that will assist NIH in enhancing its research efforts in this area.

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Opportunities (including, but not limited to):

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- Training in LGBTI health research and enhancing the cultural competency of researchers and individuals working with LGBTI persons in clinical settings, specifically how NIH can collaborate with other federal agencies to develop programs for enhancing cultural competency
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Outcome Indicators (including, but not limited to):

- Potential measures that NIH could use to indicate whether the proposed activities addressed the challenges or opportunities successfully

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Appendix E

NIH SGM RCC Roster

Rashada C. Alexander, Ph.D.[†‡] Center for Research Capacity Building National Institute of General Medical Sciences, 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	**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	**Amy Lossie, Ph.D.** Office of Disease Prevention Office of the Director, 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 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	**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	**Mary Roary, Ph.D.** National Institute of Nursing Research, 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

*Committee Co-Chairs

[†] Strategic Plan Working Group

‡Formerly in the Immediate Office of the Director, Office of the Director, NIH