Consideration of the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals

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Executive Summary

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 Health¹, 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:
 - Understand and address health inequities in LGBT populations and to increase health careseeking 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

¹ The Mental Health Category is a broad category that not only includes LGBT projects involving depression and suicide studies but also many that involve the mental health aspects of HIV/AIDS. Therefore, although a larger number of overall projects were coded for the Mental Health category further evaluation showed that few of these projects focused on depression or suicide, important health concerns in LGBT health.

- 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
- 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.

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.

Introduction

This report of the NIH LGBT Research Coordinating Committee (RCC) provides options for NIH to consider in response to the March 31, 2011 report of the Institute of Medicine (IOM), *The Health of Lesbian, Gay, Bisexual and Transgender People* (<u>http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx</u>). The options proposed by the RCC are provided along with each IOM recommendation. They reflect the RCC's review of the IOM Report and analysis of the FY 2010 NIH LGBT research portfolio and "mapping" results of that analysis to the IOM Report recommendations and related issues.

In response to a request from more than 300 researchers and Congressional interest, the NIH in 2009 commissioned the IOM Report. The IOM was charged 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." NIH also charged the IOM to "consider research training needs to foster the advancement of knowledge about LGBT health and identify impediments that hinder such advancement." The NIH charge listed possible "areas of interest," including LGBT health risks and protective factors; access to and use of health care; "the developmental process from childhood across the life course, in the context of family and social networks;" other cultural and demographic factors; and methodological challenges in LGBT health research.

In 2011, NIH leadership established the RCC, which consists of representatives nominated by 21 Institutes, Centers, and Offices (ICOs). RCC co-chairs are the NIH LGBT Research Coordinator in the Office of Extramural Research and a *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) RCC representative, who served as the NIH task manager for the IOM Report. The RCC was charged with:

"...developing and coordinating potential research and training activities to be undertaken at the NIH as a result of recommendations from the Institute of Medicine (IOM) report on LGBT health issues, research gaps and opportunities. The LGBT RCC should assess relevant past and ongoing activities across the NIH and develop recommendations for new activities focused on research and training. In addition, the committee [RCC] should develop and recommend strategies to track and monitor NIH research initiatives and progress in this area."

Overview of the IOM Report and RCC Review

The IOM Report provides the first comprehensive overview of the health of LGBT populations in the United States (U.S.) and scientific research needs. With few exceptions, the IOM found that data and research on LGBT populations' health are quite limited. Existing research has focused primarily on gay men and lesbian women and on certain health risks (e.g., HIV/AIDS, sexually transmitted infections, substance use/abuse, and mental illness). The IOM called on the NIH to implement a research agenda "to advance the knowledge and understanding of the health of lesbian, gay, bisexual and transgender populations," and take additional actions to further that goal. Table 1 summarizes the IOM Committee's recommendations and specific health conditions/risks identified as particularly important for LGBT populations.

RCC members commend the depth and breadth of the IOM report, which discussed LGBT health and health risks of these populations in the context of evolving societal attitudes towards sexual and gender minorities. The RCC also concurs with the IOM Report's emphasis on the diversity among and within

Table 1: Summary of IOM Report Recommendations and Related Issues

- 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;

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- 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;"and
 - 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.

LGBT Health Risks, Conditions, and Protective Factors Identified by the IOM LGBT Report

- 1. Stress, exposure to violence, stigma and discrimination
- 2. Access/barriers to health care
- 3. Resilience, including familial and societal factors
- 4. Depression, suicide
- 5. Substance use and abuse (alcohol, drugs, tobacco)
- 6. HIV/AIDS and other sexually transmitted infections
- 7. Certain cancers
- 8. Obesity (in lesbians)
- 9. Long-term hormone use (transgender individuals)

lesbian, gay, bisexual, and transgender populations and to consider both the shared experiences of LGBT populations that unify them and the need to avoid generalizations that obscure differences.

The IOM Report includes a detailed literature review and compilation of what is known about LGBT health and discusses health and health risks of LGBT populations. The RCC notes that while the IOM Report includes detailed discussion of a number of known diseases, disorders, health risks, and concerns of LGBT populations, much of the perspective and focus appears weighted toward psychosocial considerations, reflecting the existing literature on LGBT health. The RCC members observe that there are additional topics of importance to the missions of the individual ICOs that also merit attention. These include several conditions associated with HIV/AIDS (e.g., Kaposi's sarcoma, dementia, metabolic, and other adverse effects of antiretroviral therapies), pre-adolescent developmental processes in LGBT individuals, and intersexuality² as a gender-variant condition. The RCC also notes that some of the IOM Report recommendations are wholly or partially beyond the scope of the NIH mission and/or could be shared interests with other agencies or staff divisions in HHS. This will be discussed further under each specific recommendation where appropriate.

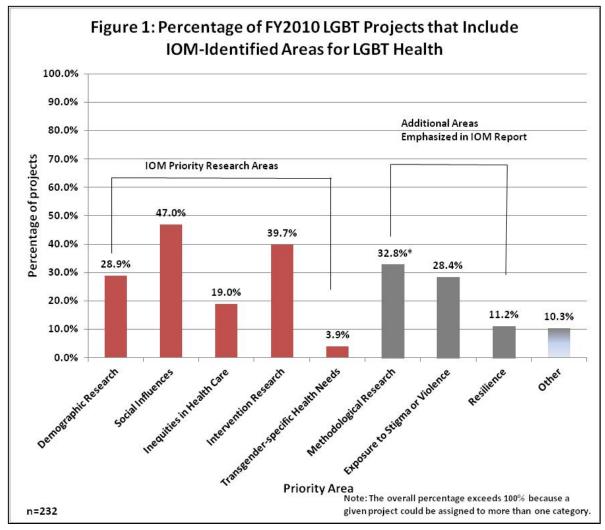
RCC Portfolio Analysis, Mapping to the IOM Report, and Potential Opportunities

The NIH has an ongoing research portfolio in the area of LGBT health. The RCC analyzed this portfolio for FY 2010 (the most recent year for which complete data were available at the time of analysis), to understand the science funded by the NIH and to "map" the portfolio to the recommendations, health risks, and conditions identified in the IOM Report as well as to additional interests or priorities of ICOs. The RCC uses the term "LGBT" as described in the IOM report.

The RCC analysis provides a snapshot of a specific fiscal year as a starting point for considering the IOM recommendations. It is important to note that this analysis focused on the science. Since the charge to the RCC did not include examining budgets, 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. Under each of the IOM recommendations, the RCC provides relevant information from the portfolio analysis, discusses how the information maps to the IOM findings, and identifies gaps and opportunities for NIH leadership to consider. The RCC opted for a conservative approach, including only those projects for which investigators explicitly identified one or more LGBT 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 LGBT populations as participants. Other limitations in the analysis are noted as appropriate in discussions of individual IOM recommendations.

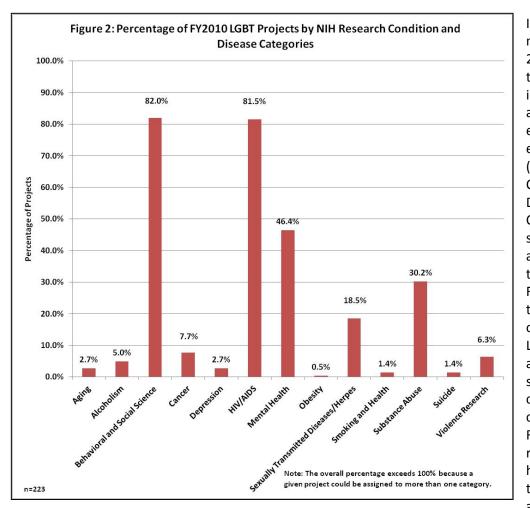
² "Intersex" is typically defined as having, at birth, atypical reproductive or sexual anatomy or a chromosomal pattern that varies from XX or XY. Other terms including "hermaphroditism" and "disorders of sexual development" have also been used to identify this condition.

IOM Recommendation 1. NIH should implement a research agenda designed to advance knowledge and understanding of LGBT health. The NIH has an ongoing research program in LGBT health which, for FY 2010, consisted of 232 projects³ addressing one or more of the areas identified by the IOM committee. Figure 1 depicts IOM-identified areas of research in the FY 2010 NIH research portfolio. The categories were coded by staff of the ICO with administrative responsibility for the projects, working



with RCC members. The "Other" category was intended to capture anything the ICOs wanted to comment on that was outside the specific IOM priority areas, for example HIV prevention research. Because a given project could be assigned to more than one category, the total exceeds 100%. A number of projects were identified as being methodological research; however, a closer examination suggests variation in how staff interpreted the term* (see Recommendation 5 for additional discussion).

³ As detailed in Appendix A, the RCC analysis focused on the parent level of projects; therefore, large networks, centers, and other research support involving multiple projects and/or subprojects were associated with a single award.



In addition to mapping the FY 2010 portfolio to the IOMidentified priority areas, the RCC examined the existing NIH RCDC (Research, Condition, and Disease Categorization)⁴ system categories associated with these projects. Figure 2 shows the distribution of the FY 2010 LGBT projects according to several RCDC categories considered by the RCC to be highly relevant to LGBT health based on the IOM Report and knowledge of

the field. A given project could be assigned to more than one of these categories, thus the total of the percentages exceeds 100%. Figure 2 indicates that much of the NIH portfolio of LGBT projects in FY 2010 was focused in Behavioral and Social Science, HIV/AIDS, Mental Health⁵, and Substance Abuse. There appears to be little research in several key health areas for LGBT populations including the impact of smoking on health, depression, suicide, cancer, aging, obesity, and alcoholism. For a full list of RCDC categories associated with the FY 2010 LGBT projects in this portfolio analysis, see Appendix B.

The IOM Report discussed LGBT health from the perspective of population characteristics including age, race/ethnicity, and the specific needs and concerns of the individual groups comprising the LGBT "umbrella" (e.g., gays, lesbians, etc.). In terms of age, the vast majority of projects included individuals

⁴ The RCDC system uses sophisticated text data mining (categorizing and clustering using words and multiword phrases) in conjunction with NIH-wide definitions used to match projects to categories. The definitions are a list of terms and concepts selected by NIH scientific experts to define a research category. The research category levels represent the NIH's best estimates based on the category definitions. <u>http://report.nih.gov/RePORT_Brochure_Web.pdf</u>

⁵ The Mental Health Category is a broad category that not only includes LGBT projects involving depression and suicide studies but also many that involve the mental health aspects of HIV/AIDS. Although a larger number of overall projects were coded for the Mental Health category further evaluation showed that few of these projects focused on depression or suicide, important health concerns in LGBT health.

age 18 and above with the majority of those studies exclusively including 18 and older and a small proportion exclusively including 21 and older. Considerably less research was conducted in children under 18⁶. Some studies included children under 18 as part of the study population but far fewer focused exclusively on under 18 or under 21 populations. While the majority of studies included adults, very few studies were limited exclusively to studying older LGBT individuals. This confirms the observation in Figure 2 that there are few FY 2010 projects focused on aging. These analyses also confirm the IOM Committee's finding that the majority of the research on LGBT health focuses on young and middle adulthood, with less in both adolescence and later adulthood.

The IOM Report focused on adolescence and not on childhood "because of limited research available on [their] awareness of, feelings about, and experiences with being LGBT;" however, the IOM Report did identify research on LGBT youth as a research opportunity. The RCC analysis also found that the NIH supports little LGBT-related, pre-adolescent research.

In examining race and ethnicity, the RCC generally found that the majority of projects either included all races/ethnicities (based on Office of Management and Budget reporting standards for race and ethnicity⁷) or focused on one or more races and/or ethnicities (for example, African- American or Hispanic gay men) due to the scientific goals of the research. Diversity of the participant pool appears fairly robust; of note, though, no current projects appear to focus on understanding if and how an individual's sexual minority status and racial and/or ethnic status interact, and if so, whether that interaction impacts health. This topic was also highlighted by the IOM as one of several important "cross-cutting perspectives" for LGBT research.

The RCC also attempted to determine which specific sexual or gender minority populations were studied by investigators. This proved somewhat challenging due to variability in how investigators described their target populations. The IOM Report noted that there was more research on gay and lesbian populations and less on bisexuals and transgender persons. Based on the information available to the RCC, it appears that the majority of FY 2010 projects focused on gay men or men who have sex with men (MSM) or more broadly recruited sexual minorities as a group. However, the RCC also found a number of projects that included or focused on bisexual men, bisexual women, and/or men who have sex with men and women (MSMW). A number of studies also included transgender people as part of the study population but few focused specifically on transgender persons. Similarly, lesbians were included in a number of the projects but fewer studies focused solely or specifically on lesbian health needs.

Consistent with the IOM Report, the RCC acknowledges that there are still large gaps and many areas of opportunity to increase understanding of broad health needs and specific health issues and concerns faced by members of the LGBT community. The portfolio analysis and mapping suggest a number of research opportunities to expand the scientific knowledge base for LGBT health. These opportunities, which the RCC has not attempted to prioritize, include but are not limited to the following research areas:

⁶ NIH defines a child as under the age of 21 (<u>http://grants.nih.gov/grants/guide/notice-files/not98-024.html</u>).

⁷ OMB 1997 standards for race and ethnicity (<u>http://www.whitehouse.gov/omb/fedreg_1997standards</u>)

- Understand and address health inequities⁸ in LGBT populations and to increase health careseeking behaviors for routine screenings, preventive care as well as care for acute and/or chronic illnesses;
- Further develop and standardize measures of sexual orientation and gender identity to inform research in LGBT health;⁹
- Understand the impact of interactions between health risks and protective factors among LGBT populations at different ages and developmental stages, over the life course;
- Understand the ways that minority stress, stigma and violence associated with sexual orientation and/or gender identity may influence health risks and outcomes, particularly in combination with minority status, such as race, ethnicity, immigration status, or low socioeconomic status;
- 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 the increased incidence or risk of certain diseases and/or conditions (e.g., eating disorders, obesity, sexually transmitted infections, etc.) in all or a subset of LGBT populations and the possible pathophysiologic processes or social determinants that are contributing factors;
- Understand treatment and/or reducing risk for depression, suicide, and other mental health conditions of different LGBT populations;
- Understand the causes and correlates of elevated rates in smoking, alcohol, and other substance abuse among LGBT individuals, including efforts to improve preventive and treatment interventions, tailored to the unique health needs of LGBT populations;
- Research to better understand differential risks and rates of cancers such as cervical cancer, breast cancer, anal cancer, Kaposi's sarcoma, and possibly lung cancer, and other types of cancer among LGBT persons;
- Research on transgender-specific health concerns including depression, anxiety, suicide risk, and the safety and efficacy of surgical sex reassignment procedures as well as clinical care and the health impact of transitioning from one gender to another, recognizing that gender identity is not necessarily limited to a fixed male/female dichotomy;

⁸ Research on health care access and quality issues reflecting "inequities in health care" could also be of interest to the Agency for Healthcare Research and Quality (AHRQ), while research on interventions to address health inequities and negative health outcomes in LGBT populations could also be of interest to AHRQ, the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Health Resources and Services Administration (HRSA). Potential collaborations with these agencies could be an opportunity to expand NIH's research portfolio in this important area.

⁹ This could be accomplished by support of NIH projects and/or workshops along with continued support of the NCHS (National Center for Health Statistics) at the CDC (Centers for Disease Control and Prevention) and other HHS efforts to address this topic.

- Research on specific needs of children diagnosed as intersex¹⁰ and their families;
- Research on the cardiovascular, endocrine, and neurological effects as well as potential cancer risks of hormone therapy in transgender and/or intersex individuals.

IOM Recommendation 2. Data on sexual orientation and gender identity should be collected in federally funded surveys administered by the Department of Health and Human Services and in other relevant federally funded surveys. Estimates of the size of the LGBT populations vary substantially because of significant methodological challenges in data collection, including issues with definitions, variability in individuals' self-identification as LGBT, heterogeneity among and within LGBT populations, small sample sizes, and lack of standardization of questions to obtain valid and reliable data on subjects' sexual orientation and gender identity. On the basis of data compiled from multiple sources, a leading researcher in this area¹¹ estimates that lesbian, gay, and bisexual individuals comprise about 3-4% of the general U.S. population and transgender persons comprise approximately 0.3% of the U.S. population. Another challenge is when and how to include individuals engaged in non-heterosexual or non-gender conforming behaviors but who do not identify with any of the specific terms used. Gates (2011) also noted that population survey data suggest about 8% of Americans have engaged in same-sex behaviors and that 11% acknowledge at least some same-sex sexual attraction.

Although this IOM recommendation largely exceeds the scope of the NIH mission, the RCC recognizes the importance of data collection efforts in gaining a better understanding of LGBT health and in continuing to support an LGBT health research portfolio by NIH. Routine collection of demographic data related to sexual orientation, gender identity, sexual behavior, and sexual attraction is a critical step in further understanding LGBT health needs. The NIH has provided support to the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC) to assist in the development and implementation of methods to incorporate questions about sexual identity in population surveys. As detailed in the HHS Secretary's *Future Recommended Actions* in the area of LGBT health, the HHS is committed to working toward increasing the number of federally funded health and demographic surveys that collect and report sexual orientation and gender identity data. For full details see: http://www.hhs.gov/secretary/about/lgbthealth.html

IOM Recommendation 3. Data on sexual orientation and gender identity should be collected in electronic health records. The IOM directed this recommendation specifically to the Office of the National Coordinator for Health Information Technology (ONCHIT) at HHS. Ensuring data collection of data on sexual orientation and gender identity in electronic health records (EHR) is generally beyond the

¹⁰ Historically, a male or female identity has been "assigned" to intersex children shortly after birth and such assignment may include surgical and/or hormonal interventions. The IOM report stated that "[a]Ithough intersexuality constitutes an additional type of "otherness" that is stigmatized and overlaps in some areas with LGBT identities and health issues, the [IOM] committee decided it would not be appropriate to include intersexuality in the study scope. The majority of individuals affected by disorders of sex development do not face challenges related to sexual orientation and gender identity, although homosexuality, gender role nonconformity, and gender dysphoria (defined as discomfort with the gender assigned to one at birth) are somewhat more prevalent among this population compared with the general population."

¹¹ Gates, G. J. (2011). How many people are lesbian, gay, bisexual, and transgender? Research Brief. The Williams Institute. The University of California at Los Angeles. <u>http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/how-many-people-are-lesbian-gay-bisexual-and-transgender/</u>

scope of the NIH mission. However, there may be opportunities for the NIH to support research on methods of data collection in EHRs and uses of such data. Other opportunities to partner with the ONCHIT or others within HHS also may exist.

IOM Recommendation 4. NIH should support the development and standardization of sexual orientation and aender identity measures. There is a critical need to develop valid and reliable methods to gather sexual orientation and gender identity information. In performing the portfolio analysis, the RCC found a few projects that include support to develop or standardize these types of measures. The NIH, through the National Institute on Minority Health and Health Disparities (NIMHD), provided support to the NCHS at CDC for their efforts to develop questions on sexual identity in the National Health Interview Survey (NHIS). The NICHD supports the NCHS' National Survey of Family Growth (NSFG) which includes questions about sexual behavior and sexual identity. The PhenX¹² initiative, supported in partnership with the National Human Genome Research Institute (NHGRI), is intended to provide investigators with high-quality, relatively low-burden measures for inclusion in genome-wide association studies (GWAS) and other large-scale research efforts thereby increasing standardization and harmonization across studies; the "sexual history" measure from the National Longitudinal Study of Adolescent Health (AddHealth) is included in the PhenX Toolkit and assesses elements of sexual orientation. This is the only measure examining sexual orientation.¹³ In addition, NIH staff members have also participated recently in HHS meetings regarding the best options and opportunities for addressing gender identity in HHS programs. While it appears that the NIH has few research projects developing or standardizing these types of measures, it is an important recommendation and has also been identified as an area of opportunity for research under Recommendation 1.

IOM Recommendation 5. NIH should support methodological research that relates to LGBT health. The IOM Report stressed methodological challenges related to furthering our understanding of LGBT health needs, particularly those surrounding how best to access small populations and develop valid approaches to analyze such data. What is also clear is that resolving methodological challenges in LGBTrelated demographic research would strengthen such research and create a foundation of understanding on which to develop specific health-related studies in these populations. In many instances, these populations are seen as "invisible" or "hidden" and therefore developing research studies to examine their health can be more challenging. Although ICOs initially identified a number of projects as "methodological research" (see Figure 1), further review of these projects suggests that staff interpreted this category fairly broadly. Closer examination of these projects reveals that only a few focused specifically on developing and/or refining methodologies to recruit hard to reach sexual and gender minority groups, as the IOM Report envisioned. Opportunities exist through participation in HHS activities in this area as well as the development of NIH workshops and/or funding opportunity announcements (FOAs) to address small/hard to reach populations with either a specific focus on LGBT populations or explicit inclusion of LGBT populations with other groups that pose similar challenges. There also may be ongoing FOAs or research activities that address small/hard to reach populations that could be expanded to include LGBT populations and their health issues.

IOM Recommendation 6. A comprehensive research training approach should be created to strengthen LGBT health research at NIH. Figure 3 shows LGBT-related projects by NIH grant

¹² PhenX project: <u>https://www.phenx.org/Default.aspx?tabid=56</u>

¹³ PhenX protocol involving questions related to sexual orientation: <u>https://www.phenxtoolkit.org/index.php?pageLink=browse.protocoldetails&id=101401</u>

mechanisms (or activity codes). The largest proportion of projects fall under the research (R) activity codes including R01, R21, R03, etc. with the next largest being cooperative agreements (U) like U01s and UM1s, followed by career development (K) awards such as K01s and K23s.

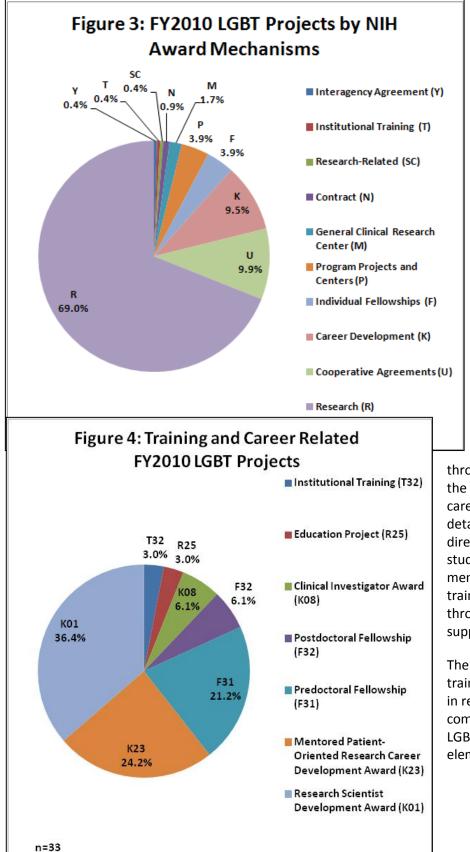


Figure 3 also demonstrates that training and career development mechanisms make up approximately

14% of the total number of projects in the FY 2010 portfolio. Of that ~14% (see Figure 4): Mentored **Research Scientist Development Award** (K01) comprises the largest number of training/career development awards with Mentored Patient-**Oriented Research** Career Development Awards (K23) and Ruth L. Kirschstein National **Research Service Awards** for Individual Predoctoral Fellowships (F31) also making up a large proportion. While the NIH has formal mechanisms (such as these) for training individuals, many students and fellows are also directly supported

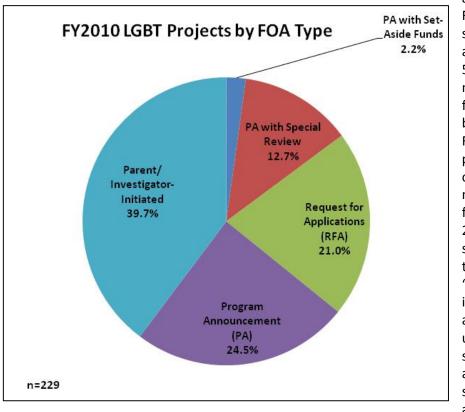
through research grants, thus the number of training and career development projects detailed in Figure 4 does not directly map to the number of students, fellows, and faculty members who may be training in LGBT health through other NIH research support mechanisms.

The RCC recognizes that training, career development in research, and cultural competency in working with LGBT populations are key elements to advancing the NIH research portfolio in LGBT health and ultimately to improving the health outcomes in LGBT persons. Opportunities to expand support for individuals desiring to train in LGBT health research could include support of more institutional training and education programs. Programs at the institutional level could provide the opportunity to "seed" the field. The challenge is how to develop institutional training programs in this area because LGBT health spans the missions of many ICOs.

An additional opportunity exists to develop formal collaborations with other HHS agencies like the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Agency for Healthcare Research and Quality (AHRQ) in the areas of cultural competency and LGBT training program development. Activities could include joint funding or joint FOAs in these areas and/or the development of webinars, workshops, or other activities to increase the cultural competency of investigators, trainees, and agency staff. In addition to more support of individual projects in the area of LGBT cultural competency, expansion of the Office of Behavioral And Social Sciences Research (OBSSR) training program aimed at strengthening behavioral and social sciences training in medical schools

(<u>http://obssr.od.nih.gov/training_and_education/bss_medical_school/index.aspx</u>) to include LGBT cultural competency, is another opportunity that could be explored.

IOM Recommendation 7. NIH should encourage grant applicants to address explicitly the inclusion or exclusion of sexual and gender minorities in their samples. Although the RCC focused on understanding the research-based recommendations of the IOM, the members recognize that inclusion of LGBT individuals in research efforts is critical for advancing knowledge of LGBT health and improving LGBT health outcomes. Inclusion threads throughout the IOM Report and is directly addressed in this recommendation. There are numerous opportunities to address the inclusion of LGBT as research participants. An important first step in accomplishing this goal is the development of reliable and valid methods for collecting information on sexual orientation and gender identity, as discussed in other recommendations. In addition, efforts can be made to continue issuing LGBT-specific and LGBT-related FOAs which would explicitly increase inclusion of these populations in research activities. There is also an opportunity to enhance inclusion by encouraging NIH extramural program staff to consider LGBTrelated health issues and their relevance to the scientific portfolios when developing potential FOAs and/or workshops and other related programmatic activities. To better understand the current inclusion of LGBT-health issues in NIH initiatives as well as how investigators succeed in getting NIH funding for LGBT health research, the RCC examined the mechanisms and FOAs by which the identified projects were submitted to the NIH. Some RCC members reported feedback from the LGBT health research community about concerns in obtaining NIH funding



and whether targeted FOAs and/or special study sections are needed for applicants' success. Figure 5 demonstrates that a number of different funding opportunities have been used to support the FY 2010 LGBT-health projects including a variety of approaches that may or may not include set-aside funds. The majority of FY 2010 projects were submitted to the NIH through general purpose "parent" FOAs, investigator-initiated applications (now captured under parent FOAs) or standard program announcements with no special review or fund setasides.

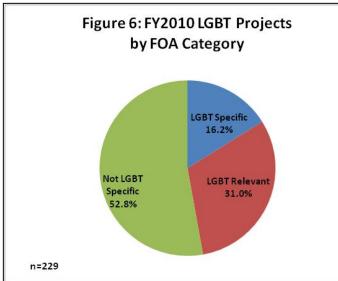


Figure 6 illustrates the distribution of projects based on whether the FOA was LGBT-specific, LGBT-related, or not related to LGBT (see Appendix A for further description of these categories). LGBT-health investigators have demonstrated success in applying for FOAs that are targeted to LGBT health or populations as well as those not targeted to LGBT health yet are appropriate for submission of LGBT health projects. Over 50% of FY 2010 projects were funded through FOAs

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that were not specific to or related to LGBT health. Identifying ways 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 another opportunity to explore.

It is also important to ensure that the LGBT health research community is aware of specific funding opportunities for LGBT health. To that end, posting a Notice in the NIH Guide summarizing funding opportunities that are directed to LGBT health or important for LGBT health could serve as an opportunity to highlight already existing programs. This could also provide an opportunity to increase awareness in the LGBT research community about "parent" FOAs and non-LGBT specific FOAs and how those are utilized to support LGBT research funded by NIH.

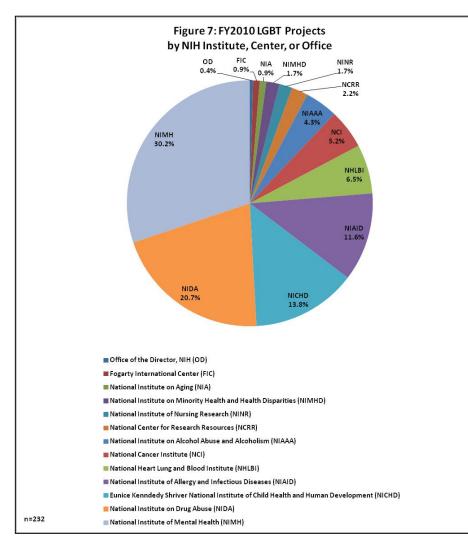
Additional Opportunities

In addition to the portfolio analysis and mapping to the IOM recommendations, the RCC considered other ways to improve LGBT health research at the NIH. Initiating and expanding existing opportunities to increase communication with the LGBT health community and foster a better understanding of the NIH organizational structure and function could be explored. Instructing investigators on how to obtain NIH grant funding as well as increasing awareness among LGBT health researchers regarding what funding opportunities are available through different mechanisms, different career levels, and different programs across the NIH will help increase LGBT health research activities. Attendance of NIH staff at LGBT health-specific research meetings and conferences could be fruitful both for NIH staff to understand specific health concerns and issues in LGBT and related populations as well as for investigators conducting LGBT research to have the opportunity to interact with NIH staff and discuss ICO missions and interests.

As in other scientific fields, having NIH staff conduct or participate in activities related to how to obtain NIH grant funding could be helpful to investigators in the field, particularly new investigators. Grantsmanship training sessions could be jointly organized across ICOs whose missions/portfolios are relevant to a given conference/workshop or centrally coordinated. In addition, a less formal approach would be for individual or groups of NIH extramural staff to reach out directly to conference organizers or investigators in the field of LGBT health to find out how to help facilitate communication between NIH and the extramural LGBT research community. Some of these types of activities are already ongoing in the community but expanded efforts would be beneficial to the NIH and the research community for LGBT health.

Having new or early career investigators in the field of LGBT health gain NIH review experience is also important for the field of LGBT health. The Center for Scientific Review (CSR) Early Career Reviewer Program presents an opportunity to integrate more LGBT health researchers into the NIH review process. This program serves to train investigators to become effective reviewers but also can help emerging researchers advance their careers by exposing them to review experience (http://public.csr.nih.gov/ReviewerResources/BecomeAReviewer/Pages/Overview-of-ECR-program.aspx).

NIH Administrative and Operational Directions



The results of the portfolio analysis highlight the need for continued research to advance the understanding of LGBT health and improve health outcomes for these populations. Figure 7 demonstrates the cross-cutting nature of LGBT health projects with a number of ICOs supporting LGBT research, training, and related activities. Together, the National Institute of Mental Health (NIMH) and the National Institute on Drug Abuse (NIDA) account for over 50% of the LGBT-related projects, with 11 other ICOs accounting for the remaining 50%.

With approximately half of the NIH

research ICOs including at least some types of LGBT research in their portfolios, ongoing trans-NIH coordination and collaboration, as has occurred in the RCC, will be critical to address the noted gaps and opportunities as well as enhance communication throughout NIH and between NIH and other HHS agencies and staff divisions. The RCC, which was charged with considering the IOM recommendations and producing the current report, provides a strong foundation for launching a trans-NIH system for action on the recommendations of the RCC. While LGBT health research would remain distributed across the ICOs as appropriate to the scientific goals of the project, a trans-NIH approach would be valuable in developing further programmatic opportunities and demonstrating NIH's long-term interest in LGBT health research. **Conclusions**

As stated in the IOM Report and reaffirmed by the RCC's portfolio analysis, it is clear that there are still numerous gaps in our efforts to understand the multiple dimensions of LGBT health and health risks. The RCC recognizes that LGBT persons and the broader LGBT community have important health concerns and needs that extend beyond association with particular diseases; however, in addition to a broader understanding of LGBT health, more research also is needed to understand the increased incidence and risk for certain diseases and conditions and to develop needed prevention strategies and

treatment approaches. The potential research topics discussed under Recommendation 1 are intended to reflect and acknowledge both areas of need.

There are many opportunities for NIH to advance in the area of LGBT health research via development of FOAs specific to LGBT health as well as FOAs in relevant health topics that also include specific mention of LGBT health concerns. It is also important to communicate that LGBT health issues may be addressed through non-targeted NIH funding mechanisms, and as demonstrated in this report, it is not necessary to wait for targeted FOAs to be successful in obtaining NIH funding in the area of LGBT health. In addition, there are opportunities for increasing research training as well as cultural competency training for investigators, trainees, and staff. Opportunities also exist for partnering with other components of HHS including but not limited to continued development of valid survey questions for assessing sexual orientation and gender identity as well as improving cultural competency.

To advance all of these efforts, further examination of the areas of LGBT health that are within a given ICO's mission could facilitate the development of IC-specific or IC-collaborative workshops and/or FOAs to increase research on specific LGBT health issues, including those addressed in the IOM Report as well as others that were not identified by the IOM but are part of the mission and priorities at the NIH. An integrated and closely coordinated trans-NIH approach to supporting LGBT health research would serve to further enhance understanding of the health needs and concerns in this community and ultimately improve public health.

Appendices

Appendix A: Methods for conducting portfolio analysis

Appendix B: List of all RCDC categories associated with LGBT FY 2010 projects

Appendix C: List of RCC member activities as well as additional activities ongoing at NIH related to LGBT

Appendix D: NIH LGBT Research Coordinating Committee Roster

Appendix A: Methods for Conducting the Portfolio Analysis

Initial portfolio analysis. The goal of this exercise was to assess the current NIH scientific portfolio relevant to LGBT health. No financial data are associated with this analysis, as it was not intended as a budget exercise. Due to the timing of the analysis, the focus was limited to awards issued in FY 2010 which provides only a snapshot of this inherently dynamic scientific portfolio.

The portfolio analysis utilized multiple methods. An initial list of projects was developed using the Research, Condition, and Disease Categorization (RCDC) system and terms related to LGBT health. This list was further refined through two processes. First, Boolean logic was applied to identify projects which contained combinations of terms relevant to LGBT 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.

It should be noted that only parent projects are included. By taking this approach, the raw number of awards (n=232) 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 LGBT individuals) or new study questions can be added to an ongoing award. Any supplements directly related to LGBT 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.

After extensive committee discussion about the scientific parameters for the portfolio analysis, it was agreed that the analysis should be limited to projects that include individuals who are lesbian, gay, bisexual, transgender, or related populations such as MSM (men who have sex with men). 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 LGBT (or related) populations, only the projects from those disease/health portfolios that include LGBT 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 LGBT 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 RCC also conducted a secondary analysis of the list of projects using the RCDC categories assigned to the each of the projects. This is illustrated in Figure 2 in the body of the report. How RCDC categories are assigned to a project is an established process¹⁴ and the RCC analysis only shows what is assigned to given project based on that process. It should be noted that nine of the projects did not have RCDC categories associated with them. A full list of terms associated with the RCC project list (n=223) is provided in Appendix B.

Population Coding. Further population coding was conducted by RCC members after finalizing the project list from the ICOs. This analysis included searching each project for details regarding the age ranges, LGBT populations (e.g., lesbians, gays, etc.), and racial/ethnic groups included. 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.

FOA Analysis. The RCC also examined what FOAs investigators utilized to submit the projects on this list. LGBT-specific FOAs specifically targeted one or more LGBT populations in the FOA program language. LGBT-related FOAs involved topics important to the health of LGBT populations but were not specifically targeting LGBT populations in the goals of the FOA. An example would be certain HIV FOAs where the intent of the FOA was not specifically targeting LGBT populations, thus for the purposes of this analysis the RCC decided to consider this "related" rather than "specific." The third category of FOAs were those that were not targeted to LGBT populations or related to specific LGBT health issues but where projects involving LGBT populations or LGBT health questions would be responsive to the goals of the FOA; examples would include non-specific parent FOAs, FOAs targeting a particular career stage (e.g., K career development awards), and research topic areas like methodology and measurement in the behavioral and social sciences, among others.

¹⁴ The RCDC system uses sophisticated text data mining (categorizing and clustering using words and multiword phrases) in conjunction with NIH-wide definitions used to match projects to categories. The definitions are a list of terms and concepts selected by NIH scientific experts to define a research category. The research category levels represent the NIH's best estimates based on the category definitions. <u>http://report.nih.gov/RePORT_Brochure_Web.pdf</u>

Appendix B: Alphabetical list of all NIH research, condition and disease (RCDC) categories assigned¹⁵ to the projects captured in the RCC portfolio analysis

Adolescent Sexual Activity	Comparative Effectiveness Research	Injury (total) Accidents/Adverse Effects	Prescription Drug Abuse
Aging		-	
Aging	Complementary and Alternative Medicine	Kidney and Urologic - Prostate Disease	Prevention
Alcoholism	Contraception/Reproducti on	Kidney and Urologic Diseases	Prevention - AIDS
Anorexia	Cost Effectiveness Research	Liver Disease	Prostate Cancer
Antimicrobial Resistance	Depression	Lung	Rehabilitation
Atherosclerosis	Diagnostic Radiology	Lung Cancer	Rural Health
Basic Behavioral and Social Science	Digestive Diseases	Mental Health	Sexually Transmitted
Behavioral and Social Science	Drug Abuse (NIDA only)	Mental Retardation (Intellectual and Developmental Disabilities (IDD))	Smoking and Health
Behavioral and Social Science - AIDS	Eating Disorders	Methamphetamine	Substance Abuse
Bioengineering	Effectiveness Research	Mind and Body	Substance Abuse Prevention
Biotechnology	Emerging Infectious Diseases	Nephritis	Suicide
Brain Disorders	Emphysema	Networking and Information Technology R&D	Suicide Prevention
Breast Cancer	Genetic Testing	Networking and Information Technology R&D - Human computer interaction and information management	Teenage Pregnancy
Burden of Illness	Genetics	Neurodegenerative	Tobacco
Cancer	Health Services	Neuropathy	Topical Microbicides
Cardiovascular	Heart Disease	Neurosciences	Translational
Cervical Cancer	Heart Disease - Coronary Heart Disease	Nutrition	Underage Drinking
Child Abuse and Neglect Research	Hepatitis	Obesity	Urologic Diseases
Chronic Liver Disease and Cirrhosis	Hepatitis - B	Pain Conditions - Chronic	Vaccine Related
Chronic Obstructive Pulmonary Disease	Hepatitis - C	Patient Safety	Vaccine Related (AIDS)
Clinical Research	HIV/AIDS	Pediatric	Violence Against
Clinical Research - Extramural	Homelessness	Pediatric AIDS	Violence Research
Clinical Trials	Human Genome	Pediatric Research Initiative	Youth Violence
Clinical Trials - AIDS	Immunization	Perinatal Period - Conditions Originating in Perinatal Period	Youth Violence Prevention
Clinical Trials - Non-AIDS	Infectious Diseases	Pneumonia	
Colo-Rectal Cancer	Injury - Childhood Injuries	Pneumonia & Influenza	

¹⁵ These RCDC category terms are what are associated with one or more of the projects captured in the RCC analysis. The RCC was not involved in assigning these categories to the projects.

Appendix C: List of additional activities at NIH related to LGBT health and research

Activities and Roles Undertaken by the Committee

The NIH LGBT Research Coordinating Committee (RCC) members were given their charge in February 2011 and began meeting every other week in the spring. Members have undertaken a number of activities including developing the parameters for the scientific portfolio analysis as well as review and consideration of the IOM Report and mapping of the recommendations to the portfolio. Members have also coordinated IC feedback on the scientific portfolio analysis and have provided feedback to the committee co-chairs on the structure of the RCC Report, the summary data presented, and the specific opportunities and details to highlight.

Members of the committee also serve on several committees or work groups within the Federal Government as well as with professional societies.

- LGBT Topic Workgroup of the Healthy People 2020 campaign. Other members have also weighed in and provided information for Healthy People LGBT Workgroup activities.
- The National Action Alliance for Suicide Prevention: Research Task Force of the LGBT Task Force.
- OMB committee examining how relationships (including same-sex partnerships) are defined in federal surveys.
- LGBT Special Interest Group of the Society for Social Work and Research

Funding Opportunity Announcements

NIH funding opportunity announcements (FOAs) are released on an ongoing basis and announced weekly in the NIH Guide for Grants and Contracts (<u>http://grants.nih.gov/grants/guide/</u>). As evidenced in the portfolio analysis (see Figure 6), 16.2% of FY 2010 LGBT projects were submitted to LGBT-specific FOAs while 31.0% were submitted to LGBT-related FOAs. Additional LGBT-specific and LGBT-related FOAs have been released through FY 2011 and FY 2012. Notably, several ICOs, led by NICHD, have recently re-released FOAs specifically directed at examining LGBT health that has taken into consideration the IOM recommendations¹⁶. Although the RCC did not specifically develop this FOA, RCC members have served as a nexus for communication during its development.

Workshops and Meetings in 2011

NIH ICOs and/or NIH staff have hosted seminars, workshops, or attended meetings involving LGBT health.

- HIV/AIDS Research Among Black MSM: Research Gaps and Opportunities (Office of AIDS Research/Office of the Director, NIH)
- Resilience among MSM (Office of AIDS Research/Office of the Director, NIH)
- Creating the World We Dream Of (Office of Intramural Training and Education, Office of the Director/NIH)

¹⁶ <u>http://grants.nih.gov/grants/guide/pa-files/PA-12-111.html</u> <u>http://grants.nih.gov/grants/guide/pa-files/PA-12-112.html</u> <u>http://grants.nih.gov/grants/guide/pa-files/PA-12-113.html</u>

- Advancing the Science of LGBT Health: The IOM Report and New Steps Research Seminar presented by Robert Garofalo, M.D., M.P.H. (National Institute on Drug Abuse)
- Achieving Health Equity for Sexual and Gender Minorities presented by Judith Bradford, Ph.D. (National Institute on Minority Health and Health Disparities)
- 1987: AIDS in America (National Library of Medicine)
- Funding Opportunities for LGBT Youth Research at the National Institute of Mental Health, presented by Dr. Susannah Allison, NIMH, at the American Psychological Association (APA) Annual Conference
- SAMHSA/HRSA Gay Pride Month Panel (Attended by NIH staff)
- Gay and Lesbian Medical Association (GLMA) Annual Conference (Attended by NIH staff)
- U.S. Department of State Conference on LGBT Rights in the Western Hemisphere (Attended by NIH staff)
- HHS LGBT Cultural Competency Training (Attended by NIH staff)
- NIH Outreach Visit to University of Pittsburgh LGBT Research Program (Office of AIDS Research/Office of the Director, NIH)
- HHS Office of HIV/AIDS Policy consultation with LGBT community (Attended by NIH staff)
- HHS Roundtables on LGBT health and data collection efforts (Attended by NIH staff)

Other NIH Activities Related to LGBT Health

- Summer Institute in LGBT Population Health at the Fenway Institute (<u>http://www.icpsr.umich.edu/icpsrweb/FENWAY/training/#a001</u>): This activity is supported by NICHD through current funding and previous awards to the Fenway Institute.
- NIH LGBT Fellows and Friends Listserv and Interest Group: This activity was initiated by NIH intramural postdoctoral fellows and its organization has been facilitated by the Office of Intramural Training and Education. Activities of the group include different types of seminars including ones on LGBT health, LGBT health policy, and employment as LGBT persons.
- The National Heart, Lung, and Blood Institute (NHLBI) participates in the MSM Working Group, a subcommittee of the HHS Blood Organ and Tissue Senior Executive Council (BOTSEC) charged with reevaluating the current policy of excluding from blood donation, males who have had sex with another male at least once since 1977.
- In 2011, the Office of Behavioral and Social Sciences Research (OBSSR) conducted a workshop on electronic health records (EHRs). Workshop participants discussed incorporating questions related sexual orientation and gender identity into EHRs but considered such collection to be premature in terms of its readiness for implementation given currently-available data on the validity and reliability of questions.
- The NIH Strategic Plan on Research on Women's Health launched in September 2010 addresses the health of lesbians, bisexual women, and transgender individuals: <u>http://orwh.od.nih.gov/strategic_plan.html</u>

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