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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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.

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.

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.

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

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, 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.

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.

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.

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.

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 (expecially transgender/transsexual/CD's [cross

		dressers],etc) due to social taboos that often keep this community closted. 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.

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, 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.

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 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 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

		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 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 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.

		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

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

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.

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.

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.

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.

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

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.