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

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.

For more information, see NIH Guide Notice, NOT-OD-13-076.

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Challenges (Comment 1)

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

APA has a longstanding concern for the health and well-being of lesbian, gay, bisexual, transgender, and intersex (LGBTI) populations, and we have supported federal government action to address LGBTI health for many years. We firmly believe that rigorous scientific research is a necessary foundation for understanding and improving the lives of LGBTI individuals.

APA applauds the recommendations of the Institute of Medicine (IOM) report The Health of Lesbian, Gay, Bisexual, and Transgender People: Building the Foundation for Better Understanding. Chapter 3 of the report details in a comprehensive manner the challenges to research with the LGBTI population. We concur with the challenges described in the IOM report. We urge NIH to continue to implement these recommendations in line with the LGBTI Research Coordinating Committee (RCC) report plans.

A particular challenge is finding the right balance between general population surveys and LGBTI specific research. Including LGBTI populations in general population research remains a priority and provides important information, such as data on incidence and prevalence of certain conditions within the LGBTI population. However, research on the unique issues facing LGBTI is also essential because many important issues for small populations cannot be understood using only general population research. We urge NIH to
fund both types of research and encourage the RCC to seek the input of subject matter experts in the field regarding the appropriate balance.

**Challenges (Comment 2)**

We strongly support the meaningful steps NIH has taken to fill gaps in knowledge and research on LGBTI health in general and, in particular, NIH supported research. In recent years NIH:

- Commissioned the Institute of Medicine (IOM) report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building the a Foundation for Better Understanding*;
- Reissued Funding Opportunity Announcements (FOA’s) on *Research on the Health of LGBTI Populations* in 2011;
- Formed the NIH LGBT Research Coordinating Committee (RCC) and released the RCC report in January 2013;
- Convened an NIH Listening Session on LGBTI Health Research to obtain feedback from the LGBTI research and advocacy communities;
- Released the *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*.

Many components of NIH worked together to develop and sponsor the *Research on the Health of LGBTI Populations* FOA’s. These announcements cover a broad range of important research questions, approaches and populations. The Institutes, Centers, and Offices (ICO’s) should make deliberate efforts to fund more research grants under these announcements. Steps the NIH Office of the Director and the ICO’s can take to promote LGBTI research through these FOA’s include:

- Ensuring proposal reviewers are knowledgeable about LGBTI research and the diversity of LGBTI individuals and communities;
- Requiring that study sections have scientists with expertise and experience in LGBTI research;
- Disseminating the *Research on the Health of LGBTI Populations* FOA Number to professional associations and LGBTI advocacy groups.

**Opportunities (Comment 1)**

**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.**

Providing funding for research on LGBTI issues is key to expanding the knowledge base on LGBTI health. Such grants support existing researchers and train the next generation. Without adequate prioritization of research funding that is inclusive of LGBTI issues in LGBTI-
specific and general population-based health research, the knowledge base will remain limited.

The Health Information Technology for Economic and Clinical Health (HITECH) Act, a part of the American Recovery and Reinvestment Act of 2009, created the Medicare and Medicaid Electronic Health Records (EHR) Incentive Programs to promote the adoption of EHR’s. Detailed patient-level data for LGBT individuals, such as those found in EHR’s, can be used to track health outcomes of LGBT individuals, monitor the health status of this population, and evaluate interventions.

The NIH provided support for an IOM workshop, titled “Sexual Orientation and Gender Identity Data Collection in Electronic Health Records: A Workshop”. This followed the IOM report recommendations for data collection regarding gender identity and sexual orientation as part of a future meaningful-use objective for EHRs in conjunction with the sponsorship of NIH targeted research. There may be additional opportunities for NIH to support research on methods of data collection and uses of such data. The RCC could convene a national consultation with external stakeholders who have experience and/or expertise in Health Information Technology (HIT) and health care delivery systems, to provide advice on developing a plan for utilizing EHRs in NIH research.

Additional issues in using EHRs include:

- The protection of personal health information to ensure confidentiality. The de-identification process must ensure safeguards, especially given the historical concerns of this population regarding stigma and discrimination.
- The lack of standardization of terms for LGBTI populations. This is an ongoing methodological issue in LGBTI research and merits specific efforts that could be coordinated by RCC across NIH.

We encourage NIH to collaborate with the Office of the National Coordinator for Health Information Technology (ONC) to develop further plans in these areas.

**Opportunities (Comment 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**

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. This
would prompt researchers to consider these groups more frequently when applying for research grants examining a broad range of health outcomes. It is anticipated that the RCC would examine how NIH can implement these recommendations.

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). It would be tasked with developing a plan to coordination and collaboration across NIH on LGBTI research. The group could also make recommendations to enhance communications between NIH and other HHS Operating Divisions.

The RCC report indicates opportunities exist to develop formal collaborations with other HHS agencies like the Substance Abuse and Mental Health Services Administration (SAMSHA) in the areas of cultural competency and LGBT training program development. For example, 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.

**Opportunities (Comment 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, including, but not limited to:**

NIH could take the following steps to effectively engage with the LGBTI health research and advocacy communities:

- Attend professional meetings and conferences of non-government advocacy organizations and professional associations with interests and agendas that include LGBTI health research and advocacy;
- Appoint academic/research and community partners who can represent diverse segments of the LGBTI community to NIH advisory bodies;
- Establish an LGBTI research advisory body to regularly engage external stakeholders;
- 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. NIH has released funding Opportunity Announcements (FOA's) on CBPR with support from multiple NIH components. [NIH Office of Behavioral and Social Sciences Research - Community Based Participatory Research Index](https://www.nih.gov/).
- Encourage NIH and collaborating ICO’s to include LGBTI populations in future FOA’s and award grants for LGBTI health research under current CBPR FOA’s;
- Convene annually at least two consultations or meetings similar to the June 27, 2013 NIH Listening Session on LGBTI Health Research to foster enhanced communications with LGBTI health research and advocacy communities.

**Opportunities (Comment 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 (both targeted and non-targeted to LGBTI health)**

NIH could engage with professional societies and present at professional conferences. For example, the American Psychological Association’s 122nd Annual Convention, which takes place in Washington, DC from August 7-10, 2014, is an opportunity for NIH to communicate with psychologists who have LGBTI research interests. NIH could consider attending the conference to provide information about NIH funding opportunities and the review process and to inform our members and other investigators about the opportunities provided by the LGBTI FOA’s. Scientists continue to report that they do not think NIH would fund research based on LGBTI topics because of past attempts of by Members of Congress and the Executive Branch to stop or constrain research related to LGBTI sexuality, substance use, and other behaviors.

**Outcome Indicators (Comment 1)**

Throughout our comments, we identified funding more research grants on LGBTI topics as the key priority. Potential measures NIH could use to indicate whether our proposed activities addressed this opportunity successfully are:

- The number of new investigator initiated LGBTI focused grant applications received;
- The number of new investigator initiated LGBTI focused grant applications awarded funds;
- The number of awards made under the LGBTI FOA’s;
- Change in the number of the above over time.