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November 18, 2013

Francis Collins, M.D., Ph.D.  
Director, National Institutes of Health  
Building 1  
9000 Rockville Pike  
Bethesda, Maryland 20892

Subject: 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 (NOT-OD-13-076)

Dear Dr. Collins:

The HIV Medicine Association (HIVMA) is pleased to offer comments on the January, 2013 report and recommendations of the NIH Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Research Coordinating Committee (RCC). HIVMA represents nearly 5,000 clinicians and researchers on the front lines of the HIV/AIDS epidemic in the U.S. and abroad.

We commend the RCC for its thoughtful and comprehensive response to the 2011 NIH-commissioned Institutes of Medicine (IOM) report: "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding." The RCC's report represents an important step forward in understanding and advancing the unique health and research needs of the LGBT community and reducing health disparities among this unique and often marginalized sub-population.

We highlight several areas of particular interest to HIVMA for the NIH's consideration moving forward:

- 1) **The importance of capturing demographic data on gender identity and sexual orientation in key national surveys – but more crucially in electronic health records (EHRs):** As the report points out, IOM Recommendation #3 urging that data on sexual orientation and gender identity (SOGI) be collected in electronic health records was directed to the Office of the National Coordinator for Health Information Technology (ONCHIT) at HHS, not to NIH.

Given that many NIH-funded clinical researchers rely on EHR, we urge the NIH to weigh in with the ONCHIT and CMS on the importance for the LGBT research enterprise of including collection of SOGI data in the core demographic section of the Stage 3 EHR meaningful use guideline.

HIVMA was among the more than 140 organizations that called upon ONCHIT for the inclusion of SOGI in meaningful use guidelines.<sup>1</sup> Such data has long been routinely collected for race and ethnicity, which has proved indispensable for researchers seeking to better understand and respond to the health needs and disparities of various sub-populations. Researchers have developed standardized measures for collecting SOGI. At the Fenway Institute in Boston, researchers have evaluated the best way to ask about sexual orientation on its patient registration form at Fenway Health, the federally-qualified health center of which it is part.<sup>2</sup> Asking about and gathering information on SOGI – on a voluntary basis – is crucial if individual providers are to provide affirmative and inclusive health care to LGBT people. Knowledge of a patient's SOGI is important to understand a patient's history and clinical care needs. As EHR data are shared through state Health Information Marketplaces, these data will become a tool for health services researchers to better understand care utilization and health outcomes for LGBT populations.<sup>3</sup>

Further valuable findings for the NIH and the ONCHIT on the clinical and research value of collecting SOGI data in EHRs, and methodologies for such data collection are outlined in the report of an October 12, 2012 National Research Council workshop on collecting sexual orientation and gender identity data in electronic health records.<sup>4</sup>

**2)The importance of an emphasis on youth in identifying LGBT research agenda gaps and opportunities:** The RCC's analysis of the NIH research portfolio has identified an excellent list of gaps and opportunities to strengthen the LGBT research enterprise across the Institutes and centers.<sup>5</sup> In addition to the identified need to understand the impact of interactions between health risks and protective factors among LGBT populations at different ages and developmental stages, over the life course,<sup>6</sup> we also recommend adding to the list a greater emphasis on LGBT youth, which was a research gap also identified by the IOM. According to the Centers for Disease Control and Prevention (CDC) data from 2010:

- 1 in 4 new HIV infections occurs in youth ages 13 to 24 years;
- About 12,000 youth – about 1,000 per month, were infected with HIV, and;
- About 60% of all youth, with HIV do not know they are infected, are not getting treated, and can unknowingly pass the virus on to others.<sup>7</sup>

We also know that young MSM of color represent the single most at risk group – rates of new infections are alarmingly rising among young black MSM, with new HIV infections **increasing** 48% from 2006 through 2009.<sup>8</sup> It will remain critical to focus research efforts on discovering the most effective interventions to reduce risk and build resilience among LGBT youth, as well as conduct studies to develop effective curricula to educate clinicians, school health and mental health professionals in addition to parents and communities about the needs of at-risk LGBT youth.

**3)The value of establishing a trans-NIH mechanism to develop an integrated approach for pursuing a robust and coordinated LGBT health research agenda:** We strongly support the RCC's recommendation

to establish a trans-NIH mechanism in order to strengthen the NIH's LGBT research portfolio by ensuring coordination, collaboration and monitoring across Institutes and Centers. Such action would bring much-needed focus to NIH's efforts to enhance our understanding of the health needs and concerns in the LGBT community and ultimately how to best address them to improve individual health outcomes and benefit public health.

Thank you for the opportunity to comment on the report, and for your consideration of our views. Please count on HIVMA as a resource and ally in NIH's efforts to move this initiative forward. For further information, I can be reached through HIVMA Policy Officer, Kimberly Miller, at [kmiller@hivma.org](mailto:kmiller@hivma.org) or (703) 740-4957.

Sincerely,



Joel Gallant, MD, MPH, FIDSA  
Board Chair, HIV Medicine Association

cc: Jacob Reider, MD, Acting Director, Office of the National Coordinator for Health Information Technology

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<sup>1</sup> The Fenway Institute, Center for American Progress, et al.: Community public comment on Stage 3 proposed Meaningful Use Guidelines submitted to Office of the National Coordinator of Health Information Technology and Center for Medicare and Medicaid Services; submitted January 14, 2013. (Accessed online 11/11/2013 at:

[www.fenwayhealth.org/site/DocServer/Stage\\_3\\_Meaningful\\_Use\\_Guidelines\\_community\\_comments\\_Jan.pdf?docID=10822](http://www.fenwayhealth.org/site/DocServer/Stage_3_Meaningful_Use_Guidelines_community_comments_Jan.pdf?docID=10822)).

<sup>2</sup> Cahill, s. and Makadon, H., "Sexual Orientation and Gender Identity Data Collection in Clinical Settings and in Electronic Health Records: A Key to Ending LGBT Health Disparities," LGBT Health, Volume 1, Number 1, 2014. (Accessed online 11/11/2013 at <http://online.liebertpub.com/doi/full/10.1089/lgbt.2013.0001>).

<sup>3</sup> Ibid., p. 37.

<sup>4</sup> National Research Council. "Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary." Washington, DC: The National Academies Press, 2013. Accessed online 11/11/2013 at: [http://www.nap.edu/catalog.php?record\\_id=18260](http://www.nap.edu/catalog.php?record_id=18260)

<sup>5</sup> "Consideration of the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals," pages 10-11, (Accessed online 11/11/2013 at: [http://report.nih.gov/UploadDocs/LGBT%20Health%20Report\\_FINAL\\_2013-01-03-508%20compliant.pdf](http://report.nih.gov/UploadDocs/LGBT%20Health%20Report_FINAL_2013-01-03-508%20compliant.pdf))

<sup>6</sup> Ibid. page 10.

<sup>7</sup> Centers for Disease Control and Prevention (CDC), "Vital Signs: HIV Among Youth in the US Protecting a Generation," November, 2012. (Accessed online 11/11/2013 at <http://www.cdc.gov/vitalsigns/hivamongyouth/>).

<sup>8</sup> Centers for Disease Control and Prevention (CDC), "HIV Among Youth," (Accessed online 11/11/2013 at: <http://www.cdc.gov/hiv/risk/age/youth/>).