

NIH Fenway Institute public comment on health research needs of LGBTI populations

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Judith Bradford, PhD
Director, The Center for Population Research in LGBT Health
Co-Chair, The Fenway Institute

Kenneth Mayer, MD
Medical Research Director
Co-Chair, The Fenway Institute

FACULTY

Stephen Boswell, MD
Senior Research Scientist

Aaron J. Blashill, PhD
Affiliated Investigator

Sean Cahill, PhD
Director of Health Policy Research

Patricia Case, ScD, MPH
Senior Research Scientist

Kerith J. Conron, ScD, MPH
Research Scientist

Harvey Makadon, MD
Director, National LGBT Health Education Center

Matthew Mimiaga, ScD, MPH
Affiliated Investigator

Jennifer Mitty, MD, MPH
Affiliated Investigator

Conall O'Cleirigh, PhD
Affiliated Investigator

David W. Pantalone, PhD
Research Scientist

Lori Panther, MD, MPH
Research Scientist

Sari L. Reisner, MA
Associate Research Scientist

Steve Safren, PhD
Affiliated Investigator

S. Wade Taylor, PhD
Associate Research Scientist

Marcy Gelman, RN, MSN, CRNP, MPH
Clinical Research and Programs Director

Aimee Van Wagenen, PhD
Director of Administration and Operations

The Fenway Institute at Fenway Health offers the following recommendations on the health and health research needs of lesbian, gay, bisexual, transgender and intersex (LGBTI) populations. The Fenway Institute is an LGBT-focused, interdisciplinary center for research, training, education and policy development. It is the research division of Fenway Health, a federally qualified health center that serves LGBT people and the broader community. Fenway has been at the forefront of HIV prevention and care since the emergence of the HIV/AIDS epidemic in 1981. Our recommendations for health research affecting LGBT populations reflect the collective wisdom of Fenway Institute faculty, who are leading research studies examining LGBT demography and LGBT health disparities, including HIV.

We organize our comment using the research areas articulated by the Institute of Medicine Committee on LGBT Health Issues and Research Gaps and Opportunities. After these suggestions, we make recommendations regarding the way NIH research proposals on LGBT health are reviewed.

Demographic research

Data drive policy, including public health and prevention policy. The dearth of data on LGBT people leads to a lack of attention to this population, or a belief that their experiences are the same as those of heterosexuals. Data are essential to identifying disparities in access to care, quality of care, and outcomes. Specifically, we believe the following areas of focus would improve our understanding of LGBT health, a key to eliminating these disparities, which is a key goal of Healthy People 2020.¹

Youth

Reviews of the peer reviewed literature indicate a dearth of research on LGBT youth, and especially racial/ethnic minority LGBT youth², immigrant youth or children of immigrant parents³, and LGBT youth growing up in rural parts of the United States.⁴

1 U.S. Department of Health and Human Services. *Healthy People 2020. Lesbian, gay, bisexual and transgender health.*

<http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>.

Accessed November 4, 2011.

² Ryan, C. (2000). *Analysis of the content and gaps in the scientific and professional literature on the health and mental health concerns of lesbian, gay and bisexual youth.* Unpublished manuscript, American Psychological Association's Healthy Lesbian, Gay and Bisexual Students Project. Ryan, C. (2002). *A review of the professional literature & research needs of LGBT youth of color.* Washington: National Youth Advocacy Coalition. Both cited in Cianciotto, J. & Cahill, S. (2012). *LGBT Youth in America's Schools.* University of Michigan Press. 156-157.

- Research is needed to examine the differences among the experiences of LGBT youth of color from different racial and ethnic groups.⁵ How do race, ethnicity, and culture influence LGBT identity development and disclosure of sexual orientation and gender identity?⁶
- According to the Gay, Lesbian and Straight Education Network, LGBT youth in rural areas are less likely than youth in suburban and urban parts of the U.S. to report school-based interventions supportive of LGBT youth, including Gay Straight Alliances, reference to LGBT issues and individuals in textbooks, LGBT-specific resources in libraries, and access to LGBT resources via Internet connections at school. How do these regional variations correlate with measures of educational achievement, and psychological and social well-being?⁷
- Research is needed on out-of-home youth, i.e. youth who are homeless, in foster care, in juvenile detention, or in a congregate living facility related to mental health and/or substance use. Most lesbian, gay and bisexual (LGB) youth research is school-based, such as the Youth Risk Behavior Survey. While some out-of-home youth are in school, many are not. The disparities in health risk behaviors among LGB youth documented in YRBS data from seven states and six cities⁸ may understate the risks facing LGB youth who are not living in their homes of origin.
- How many school-age youth have LGBT parents? What are their experiences? The National Lesbian Family Study found that at ten years old, 43 percent of children of lesbian parents reported experiencing homophobia.⁹ A 2008 GLSEN survey found that most LGBT parents worried that their children would have problems in school because of having an LGBT parent. Nearly one-quarter of the youth in the study reported that they felt unsafe at school because of having an LGBT parent. Sixty-four percent of student heard anti-gay remarks in school “frequently” or “often,” and 18 percent “frequently” or “often” heard negative remarks specifically because of having an LGBT parent. Twenty-eight percent heard negative remarks about LGBT families from school faculty or staff.¹⁰

³ Ryan, C. (2002). *A review of the professional literature & research needs of LGBT youth of color*. Washington: National Youth Advocacy Coalition. Cianciotto & Cahill (2012), 156-157.

⁴ Cianciotto & Cahill (2012), 157-158.

⁵ Many of these youth research recommendations were first made in Cianciotto, J. & Cahill, S. (2012), *LGBT Youth in America's Schools*, University of Michigan Press, 155-172.

⁶ Ibid.

⁷ Kosciw, J. G., Diaz, E. M., & Greytak, E. A. (2008). *2007 national school climate survey: The experiences of lesbian, gay, bisexual and transgender youth in our nation's schools*. New York: Gay, Lesbian and Straight Education Network. Retrieved July 23, 2010, from http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/001/1290-1.pdf.

⁸ CDC *Morbidity and Mortality Weekly Report*, June 6, 2011

⁹ Russell, S., Seif, H., & Truong, N. (2001). School outcomes of sexual minority youth in the United States: Evidence from a national study. *Journal of Adolescence*, 24, 111–27.

¹⁰ Kosciw, J. G. & Diaz, E. M. (2008). *Involved, invisible, ignored: The experiences of lesbian, gay, bisexual and transgender parents and their children in our nation's K–12 schools*. New York:

- What are the similarities and differences between the experiences of LGBT-identified youth and children of LGBT parents? Do they experience harassment and discrimination differently?¹¹
- NIH should work with the Centers for Disease Control and Prevention to encourage more states and large cities to add sexual orientation and gender identity questions to the Youth Risk Behavior Surveys conducted in all 50 states. Currently only seven states and six cities ask about sexual orientation—either LGB identity, same-sex behavior, or both. Massachusetts is taking steps to add a gender identity question to its YRBS; it will be the first state to do so. Encouraging more states and cities to gather sexual orientation and gender identity data through YRBS would dramatically increase our understanding of how in-school LGBT youth experience adolescence and young adulthood, and disparities in health risk behaviors. A larger pooled data set, which would be possible were more states and cities to allow LGBT youth to self-identify, would also allow us to better understand racial/ethnic disparities and differences within the LGBT youth population. For example, in Massachusetts Asian American LGB youth are more likely than LGB youth of other racial/ethnic backgrounds to skip school due to feeling unsafe. Is this also the case for Asian LGB youth in Texas or California? We don't know, but asking sexual orientation questions on YRBS there would allow us to say whether or not this is the case and prioritize targeted interventions, including structural/policy interventions, as appropriate.

Elders

- NIH should work with the CDC to encourage states to add sexual orientation and gender identity questions to the Behavioral Risk Factor Surveillance Survey, including for people age 65 and over. This would allow us to gather a population-level sample of LGBT elders in the United States.
- Gerontological research distinguishes among the “young-old,” ages 65 to 74, the “old-old,” 75-84, and the “oldest old,” 85 and older. In general, frequency of illnesses and chronic conditions increases with age.¹² The majority of research on LGBT elders looks at the “young-old” LGBT cohort. More research is needed on the old-old and oldest-old LGBT people.
- There is a dearth of research on LGBT elders from racial and ethnic minority backgrounds and LGBT elders living in rural areas. How are social support networks and experiences of anti-LGBT discrimination different in various racial/ethnic groups and across geographical differences?

Gay, Lesbian and Straight Education Network. Retrieved September 25, 2010, from http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/001/1104-1.pdf.

¹¹ Cianciotto & Cahill, 159.

¹² McMahan S, & Lutz R. (2004). Alternative therapy use among the young-old (ages 65 to 74): An evaluation of the MIDUS database. *Journal of Applied Gerontology*, 23(2),91-103.

- It would be useful to better understand resiliency factors among LGBT elders. What are the factors that can reduce the likelihood of comorbidities and social isolation, and support healthy aging in place, i.e. in the elder's home?

Data collection in clinical settings and in Electronic Health Records

The Institute of Medicine's Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities recommended in 2011 that sexual orientation and gender identity (SOGI) questions be asked in clinical settings and in electronic health records (EHR) and be standardized to allow for the comparison and pooling of data to analyze the unique needs of LGBT people.¹³ While that recommendation was directed toward the Office of the National Coordinator of Health Information Technology (ONCHIT) and not NIH, the NIH should weigh in with ONCHIT, since many NIH-funded clinical researchers rely on EHR for their research. Gathering of and tracking of SOGI data in EHR as a standard clinical practice would lead to an unprecedented resource for understanding LGBT health and reducing disparities. A provider's knowledge of a patient's sexual orientation and gender identity is essential to providing appropriate prevention screening and care.¹⁴ Patients who disclose their sexual orientation identity to health care providers may feel safer discussing their health and risk behaviors as well.¹⁵

Gathering LGBT data in clinical settings is consistent with efforts of the U.S. Department of Health and Human Services to gather health data on LGBT populations as authorized under Section 4302 of the Affordable Care Act.¹⁶ Healthy People 2020 also calls for gathering sexual orientation data by clinicians.¹⁷ At a February 6, 2013 public meeting, an ONCHIT staff person noted that there was "overwhelming support" in public comment submitted for requiring that providers ask these questions. Many health care organizations are already moving forward with efforts to gather such data in EHR, including the Mayo Clinic in Minnesota and Beth Israel Hospital in New York City. Gathering data on sexual and gender identity in EHR will improve our understanding of LGBT disparities, and help improve clinicians' conversations with patients about LGBT issues. Improved patient-provider communication about LGBT issues could be an important step toward reducing health disparities affecting this population.

LGBT health and incarceration

¹³ Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine, *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*, Washington, DC: National Academies Press, 2011.

http://www.nap.edu/catalog.php?record_id=13128.

¹⁴ Makadon, HJ. Ending LGBT invisibility in health care: The first step in ensuring equitable care. *Cleveland Clinic Journal of Medicine*. 2011; 78: 220-224.

¹⁵ Klitzman, RL, Greenberg, JD. Patterns of communication between gay and lesbian patients and their health care providers. *J Homosex*. 2002; 42(4); 65-75.

¹⁶ U.S. Department of Health and Human Services. Affordable Care Act to improve data collection, reduce health disparities. News release. June 29, 2011.

www.hhs.gov/news/press/2011pres/06/20110629a.html

¹⁷ Health care providers should "appropriately inquire about and be...supportive of a patient's sexual orientation to enhance the patient-provider interaction and regular use of care."

There is a dearth of research on how incarceration and involvement with the criminal justice system factors into LGBT people's lives. A recent HIV prevention study with Black gay and bisexual men found high rates of criminal justice system involvement.¹⁸ Gay men and transgender women are at disproportionate risk for sexual and physical abuse in prison.¹⁹ LGBT youth in detention experience physical, sexual, and emotional abuse from heterosexual peers and adult staff.²⁰ According to the U.S. Bureau of Justice Statistics, non-heterosexual youth are twice as likely to report being sexually victimized when in detention, and ten times as likely to report being victimized by another youth detainee. A striking 11.2% of non-heterosexual youth report sexual victimization by facility staff versus 10.2% of heterosexual youth.²¹ Research is needed on the role incarceration and criminal justice involvement plays in LGBT people's lives, and how these experiences affect LGBT people's health. Research could also inform trainings to reduce sexual victimization of LGBT people in prison and juvenile detention.

Social influences on the lives of people

One cross-cutting perspective that "should inform research on LGBT health," according to the groundbreaking 2011 Institute of Medicine report on LGBT health, is social ecology, which emphasizes the significance of social context and social determinants of health. These include interpersonal relationships and social institutions—such as families, schools, and faith communities—that can shape one's development as an LGBT person.²²

- Research should address trauma experienced by LGBT individuals during childhood and adolescence, and the mental health effects of such trauma.
- What is the impact of single-sex education on transgender and gender-nonconforming youth?
- What is the role of the Internet and social media in LGBT identity and community development, particularly among rural and racial/ethnic minority LGBT youth, and among LGBT elders? Particularly for youth, these technological advances can reduce social isolation and allow them to find peer support and supportive community-based resources. However, webcams,

¹⁸ Brewer R., Magnus M., Kuo I., et al. Exploring the relationship between incarceration and HIV among Black men who have sex with men in the U.S. *JAIDS*. October 2013.

¹⁹ Giller, O. (2004, summer). Patriarchy on lockdown: Deliberate indifference and male prison rape. *Cardozo Women's Law Journal*, 10(659). Accessed January 20, 2006, from <http://www.spr.org/en/academicarticles/giller.html>. Mariner, J. (1999). *No escape: Male rape in U.S. prisons*. New York: Human Rights Watch. *Roderick Keith Johnson v. Gary Johnson*, 385 F.3d 503, 512 (5th Cir. 2004).

²⁰ Majd K, Marksamer J, & Reyes C. *Hidden injustice: Lesbian, gay, bisexual and transgender youth in juvenile courts*. Washington, DC: Legal Services for Children, National Juvenile Defender Center, and National Center for Lesbian Rights. 2009. http://www.equityproject.org/pdfs/hidden_injustice.pdf. Accessed January 15, 2013.

²¹ Beck A, Harrison P, & Guerino P. *Bureau of Justice Statistics Special Report: Sexual victimization in juvenile facilities reported by youth, 2008-09*. Washington, DC: U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. 2010. <http://bjs.ojp.usdoj.gov/content/pub/pdf/svjfry09.pdf>. Accessed January 15, 2013.

²² Institute of Medicine, Board on the Health of Select Populations, Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*, Washington, DC: National Academies Press, 2011.

- texting, and other social media technology can also offer new fora for bullying.²³ How are these new technologies shaping LGBT youth identity development, including coming out and experiences of victimization?
- Do openly LGBT role models—such as teachers, guidance counselors, family members, and elected officials—serve as a resiliency factor for LGBT youth and adults?
 - Another helpful cross-cutting theoretical perspective articulated in the 2011 Institute of Medicine report on LGBT health is the life course perspective,²⁴ which holds that social context, structural factors, and age cohort influence aging processes.²⁵ Different age cohorts have had different experiences with anti-gay bias, which influence LGBT individuals' attitudes toward social institutions and willingness to be "out" to health care and service providers. What are the specific experiences of LGBT elders in a wide range of senior settings, from assisted living and nursing homes to senior centers and elder housing communities? Opinion research indicates that older Americans are more likely to hold anti-gay views than younger age cohorts.²⁶ Older Americans are also more likely to hold inaccurate beliefs about the casual transmission of HIV.²⁷ How do these heterosexual peer attitudes toward homosexuality and HIV affect the experiences of older LGBT people in mainstream senior settings?
 - LGBT veterans often have negative associations of their military service related to anti-gay prejudice, the stress of hiding their sexuality, or a sexuality-related dishonorable discharge; this can cause them not to access veteran services, including health care. The Veterans' Health Administration serves nearly 9 million individuals each year and is the largest provider of HIV/AIDS care in the U.S. LGB veterans experience higher rates of suicidal ideation than heterosexual veterans²⁸ and may also suffer disproportionately from "trauma from childhood adversity interacting with military trauma," according to Blosnich, Bossarte, & Silenzio.²⁹ What are other health disparities experienced by LGBT veterans? How do LGBT veterans experience VA health care and other services, like housing assistance, congregate meals, and support groups?

Inequities in health care

²³ Cianciotto & Cahill, 3, 45-46.

²⁴ Ibid.

²⁵ Elder G (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly*, 57(1): 4-15.

²⁶ Anderson R., & Fetner, T. (2008). Cohort differences in tolerance of homosexuality: Attitudinal change in Canada and the United States. *Public Opinion Quarterly*, 47(2), 311-330.

²⁷ KFF (2010). *2009 survey of Americans on HIV/AIDS*. Retrieved from <http://www.kff.org/kaiserpolls/7890.cfm>. Accessed September 12, 2012.

²⁸ Blosnich J., Bossarte R., & Silenzio V. (2012). Suicidal ideation among sexual minority veterans: Results from the 2005-2010 Massachusetts Behavioral Risk Factor Surveillance Survey. *American Journal of Public Health*. Supplement 1. Vol 102 (S1), S44-S47.

²⁹ Blosnich J., Bossarte R., & Silenzio V. (2012). Blosnich et al. respond. *American Journal of Public Health*, 102(8), 1-10.

- The 2011 IOM report and Healthy People 2020 summarized LGBT health disparities. There is a need for large-scale, national longitudinal research on LGBT people looking at a broad range of health issues.
- LGB youth are more likely to engage in a wide range of health risk behaviors than heterosexual youth. These include suicide, substance use, sexual risk behavior—including earlier age of initiation, greater number of lifetime partners, and higher rates of pregnancy or getting someone pregnant—violence, and weight management (taking diet pills, anorexia/bulimia). A CDC analysis of YRBS data from seven states and six cities shows that gay and lesbian students and those reporting only same-sex behavior were 64% more likely than those identifying as heterosexual or reporting only opposite-sex behavior to report health risk behaviors. Bisexuals were 76% more likely.³⁰ Research on the wide range of health risk behaviors among LGBT people is needed, as well as research on the intersection of sexual orientation and gender identity with race/ethnicity in health risk behaviors. Such research could inform interventions to reduce these behaviors and lead to better health outcomes among LGBT people. Inclusion of gender identity questions in YRBS and BRFSS would allow us to better understand health risk behaviors among transgender people.
- Lesbians are more likely than heterosexual and bisexual women to be overweight and obese, increasing their risk for cardiovascular disease, lipid abnormalities, glucose intolerance, and morbidity related to inactivity.³¹ Research to better understand obesity and overweight among lesbian and bisexual women is needed to inform prevention efforts and weight loss interventions.
- Intersectionality, another cross-cutting perspective used in the 2011 IOM report, focuses on individuals' complex, multiple identities and experiences. Racial/ethnic and LGBT health disparities can intersect: two groups more likely to be overweight or obese are Black women³², and lesbians.³³ Black lesbians exhibit high rates of obesity.³⁴ Black lesbians should be a priority population in

³⁰ Kann L., Olsen E., McManus T., et al. Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12—Youth Risk Behavior Surveillance, Selected Sites, United States, 2001-2009. *Morbidity and Mortality Weekly Report*, Atlanta: Centers for Disease Control and Prevention, June 6, 2011. Vol. 60.

<http://www.cdc.gov/mmwr/pdf/ss/ss60e0606.pdf>. Accessed November 14, 2013.

³¹ Boehmer U, Bowen DJ, Bauer GR. Overweight and obesity in sexual minority women: evidence from population-based data. *Am J Pub Health*. 2007; 97: 1134-1140. Cited in Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, Landers S. Sexual and gender minority health: What we know and what needs to be done. *Am J Public Health*. 2008; 98: 989-995.

³² Office of Minority Health, U.S. Department of Health and Human Services (no date). Obesity and African Americans.

³³ Mayer K., Bradford J., Makadon H., Stall R., Goldhammer H., Landers S. Sexual and gender minority health: What we know and what needs to be done. *Am J Pub Health*. 2008; 98: 989-995.

³⁴ Dibble, S., Eliason, M., Crawford, B. (2012). Correlates of wellbeing among African American lesbians. *Journal of Homosexuality*. 59: 820-838.

- obesity research and prevention programs; culturally competent programs designed for Black lesbians will be most effective.
- Lesbians and bisexual women experience cervical cancer at the same rate as heterosexual women, but are much less likely to get routine Pap tests to screen for cervical cancer.³⁵ Cervical cancer screening and treatment disparities also affect Black and Latina women, most of whom are heterosexual. Research to understand the how to increase cancer screening and improve treatment outcomes among lesbians, especially Black and Latina lesbians, is needed.
 - Lesbians are less likely to have had a mammogram than heterosexual women, even though they may be at elevated risk for breast cancer due to nulliparity.³⁶ Black and Latina women also experience disparities in breast cancer screening and treatment outcomes. Research is needed to understand barriers to breast cancer screening for lesbians, especially Black and Latina lesbians.
 - LGBT people of color are disproportionately victimized by hate violence, according to the National Coalition of Anti-Violence Projects. Of more than 2,000 incidents reported in 2011, 50% of victims were Black, Latino, Asian or Native American (whereas racial/ethnic minorities are about 30% of the overall population). Eighty-seven percent of the 30 individuals killed in anti-LGBT hate crimes in 2011 were people of color.³⁷ The NIH should fund research on violence victimization of LGBT people, and why hate violence disproportionately affects LGBT people of color. Such research could inform prevention interventions as well as restorative justice approaches to anti-LGBT hate violence.
 - The Massachusetts Behavioral Risk Factor Surveillance Survey found poorer health among bisexual respondents compared with gay, lesbian, and heterosexual respondents, as well as higher rates of mental health issues and smoking.³⁸ Often bisexual respondents are combined with gay male and lesbian respondents; this can skew results, as often bisexual health outcomes and risk behaviors are significantly worse than those of gay men and

³⁵ Valanis BG, Bowen DJ, Bassford T, Whitlock E, Charney P, Carter RA. Sexual orientation and health: Comparisons in the Women's Health Initiative sample. *Arch Fam Med*. 2000;9(9):843-853. Kerker BD, Mostashari F, Thorpe L. Health care access and utilization among women who have sex with women: Sexual behavior and identity. *J Urban Health*. 2006;83(5):970-979.

³⁶ Cochran SD, Mays VM, Bowen D, et al. Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women. *Am J Public Health*. 2001;91(4):591. Diamant AL, Schuster MA, Lever J. Receipt of preventive health care services by lesbians. *Am J Prev Med*. 2000;19(3):141.

³⁷ National Coalition of Anti-Violence Programs, *Hate violence against lesbian, gay, bisexual, transgender, queer, and HIV-affected communities in the United States in 2011. A report from the National Coalition of Anti-Violence Programs*. New York: New York City Anti-Violence Project, 2012.

http://www.avp.org/storage/documents/Reports/2012_NCAVP_2011_HV_Report.pdf.

Accessed May 8, 2013.

³⁸ Conron, KJ, Mimiaga, MJ, Landers, SJ. A population-based study of sexual orientation identity and gender differences in adult health. *Am J Pub Health*. 2010; 100(10); 1953-1960.

lesbians.³⁹ NIH should fund research to understand bisexual health disparities related to risk behaviors and mental health, and encourage existing health surveys to add questions that would capture information about bisexual identity and same-sex behavior.

- Minority stress among LGB people is caused by experiences of antigay prejudice, expectations of such events, the internalization of societal attitudes, and anxiety related to concealment and disclosure.⁴⁰ Similar factors are probably at play with transgender people as well. Social stigma and discrimination create a stressful social environment that has a significant negative impact on the health of LGBT individuals.⁴¹ Research to better understand how minority stress affects the health of LGBT people, and how sexual/gender minority stress can intersect and interact with racial/ethnic minority stress, is needed.
- Given the prioritization of LGBT health disparities by the federal government in recent years, and the urgent need for more research on LGBT health disparities and resiliencies, we request the creation of an Office of Lesbian, Gay, Bisexual and Transgender Health to be located in the NIH Director's office.
- Training programs should be developed and expanded to provide skills and capacity to emerging researchers, including graduate students in professional and academic training programs, to conduct research in LGBT health.
- We encourage NIH Director Dr. Francis Collins to convene leaders from different institutes across NIH to better understand which institutes are taking steps to increase their focus on LGBT health research and which could do more to incorporate LGBT health in meaningful ways.

Intervention research

- LGBT people are 1.5 to 2.5 times as likely as heterosexuals to smoke cigarettes.⁴² Rates of alcohol and other substance use are also elevated compared to heterosexuals.⁴³ These risk behaviors could lead to higher risk of cardiovascular disease and certain cancers. Research is needed to better understand the correlates of tobacco and substance use among LGBT people to inform prevention strategies and cessation interventions.
- Thanks to antiretroviral medications, and as people age into their 50s, 60s and beyond with HIV, more people living with HIV/AIDS (PLWHA) are getting non-

³⁹ Matthews D., Blosnich J., Farmer G., & Adams B. (2013). Operational definitions of sexual orientation and estimates of adolescent health risk behaviors. *LGBT Health*. 1(1). 42-59.

⁴⁰ Meyer I, Northridge M (2007). *The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual and transgender populations*. Springer.

⁴¹ Ibid.

⁴² Lee J., Griffin G., Melvin C. Tobacco use among sexual minorities in the USA, 1987 to May 2007: A systematic review. *Tobacco Control* 2009;18:275-282.

⁴³ Song Y., Sevelius J., Guzman R., Colfax, G. Substance use and abuse. *The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Health*. (Makadon H., Mayer K., Potter J., Goldhammer H., eds.). Philadelphia: American College of Physicians. 2008. 209-247.

AIDS related cancers. Smoking rates and other health risk behaviors are elevated among PLWHA, at least half of whom are gay and bisexual men and transgender women.⁴⁴ Research on the intersection of HIV and cancer is needed to develop prevention and cessation interventions to reduce rates of smoking and other risk behavior among PLWHA.

- LGBT people experience barriers to accessing mental health and substance use treatment. Anticipatory fear of discrimination in mental health services⁴⁵ and actual experiences of discrimination in mental health and substance use services⁴⁶ cause LGBT people to access these services at lower rates. Lack of provider training in LGBT mental health and substance use counseling is also a barrier and a cause of culturally incompetent treatment.⁴⁷ Implementation research and evaluation of trainings of existing and new providers in LGBT mental health and substance use issues is needed.
- Surveys of both patients⁴⁸ and providers⁴⁹ indicate that prejudicial treatment occurs in clinical settings and that anti-LGBT attitudes among providers are widespread. Many LGBT people report discriminatory or culturally incompetent care, or fear such substandard care.⁶ The legacy of homosexuality and gender variance being treated as pathological by the psychiatric and medical professions has shaped LGBT communities' often negative and distrustful attitudes toward the health care establishment; this may be especially pronounced among older LGBT people. Health professionals and administrative staff need training in LGBT cultural competence to be able to provide culturally competent, affirming care. Evaluation research of such trainings can inform best practices. Research and evaluation of the state of LGBT health education in medical and health professional schools and in continuing medical education programs is also needed.
- Providers and clinical staff should be trained to appropriately gather information on sexual orientation and gender identity (SOGI) from patients for inclusion in EHR. It is important to study the most effective ways to gather SOGI information in order to optimize the data collection using ways that are most acceptable to consumers.
- Gay and bisexual men and transgender women experience a syndemic of social rejection, violence victimization, mental health and substance use

⁴⁴ Burkhalter, J., Cahill, S., Shuk, E., et al. (2012, October 4, advance published online). At the Intersection of HIV/AIDS and Cancer: A Qualitative Needs Assessment of Community-Based HIV/AIDS Service Organizations. *Health Education and Behavior*.

⁴⁵ Burgess D, Lee R, Tran A, van Ryn M. Effects of perceived discrimination on mental health and mental health services utilization among gay, lesbian, bisexual and transgender persons. *Journal of LGBT Health Research*. 2007; 3: 1-14.

⁴⁶ Willging CE, Salvador M, Kano M. Unequal treatment: Mental health care for sexual and gender minorities in a rural state. *Psychiatric Services*. 2006; 57: 867-870.

⁴⁷ Ibid.

⁴⁸ Lambda Legal. *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT People and People with HIV* (New York: Lambda Legal, 2010).

⁴⁹ Smith D, Mathews W (2007). Physicians' attitudes toward homosexuality and HIV: Survey of a California medical society-revisited (PATHH-II). *Jnl Homosexuality*. 52(3-4):1-9.

burden, and health risk behaviors, including sexual risk behaviors.⁵⁰ They also experience high rates of intimate partner violence.⁵¹ Research is needed to develop interventions that address these syndemic factors to more effectively reduce vulnerability to HIV infection among men who have sex with men (MSM), especially Black and Latino MSM.

- What are the elementary school experiences of LGBT youth, the children of LGBT parents, and youth who are perceived to be LGBT, and what successful interventions, if any, have worked at those grade levels?
- How do we foster resiliency among LGBT youth? What are protective, nurturing factors that can be promoted to LGBT youth to counter the effects of social stigma, prejudice, and social isolation? What are the correlates of success in school and adolescence and young adulthood for LGBT youth? How do youth avoid health risk behaviors?⁵²
- What interventions help transgender and gender-nonconforming youth to deal effectively with harassment and violence while remaining in school?
- How do community-based LGBT groups support youth and school communities? What are the connections and distinctions between school-based and community-based groups?
- How do Gay-Straight Alliances function to support LGBT and questioning youth, and as sites of civic engagement and leadership development? What is their impact on school environment, personal development, and the community at large?
- What are the public health effects of institutional practices that affirm LGBT identities and laws and policies that prohibit discrimination on the basis of real or perceived sexual orientation and gender identity and recognize LGBT families?
- Family acceptance has been shown protective of LGB youth; family rejection is a risk factor for unprotected sex, substance use, and other behaviors.⁵³ City health departments are promoting family acceptance as a resiliency factor for LGBT youth. Parents who exhibit a strong degree of religiosity may reject their children for being LGBT. Research is needed to evaluate interventions promoting family acceptance in order to develop effective interventions that can be scaled up to shift social norms toward family acceptance of LGBT youth.
- Clinical trials of pre-exposure prophylaxis for HIV prevention (PrEP) should continue with priority populations, including serodiscordant opposite-sex and

⁵⁰ Stall R., Herrick A. Intervention implications of a syndemics approach to HIV prevention among gay men. HIV Prevention Trials Network. No date.
<http://www.hptn.org/web%20documents/DPWG/Mar2010Mtg/RStallSyndemicInterventions.pdf>. Accessed November 14, 2013.

⁵¹ Greenwood, G., et al., Battering victimization among a probability-based sample of MSM. *AJPH* 2002 92:1964-1969.

⁵² Cianciotto & Cahill, 168-172.

⁵³ Ryan, C., Huebner, D. and Sanchez, J. (2009) Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. *Pediatrics* 123(1): 346-352.

same-sex couples, as well as most at risk populations such as MSM, transgender women, injection drug users, and sex workers. Studies of intermittent PrEP, non-tenofovir-based regimens, and non-oral modes of administration are important, so that the most cost-effective, safest, and most acceptable regimens are available to the diverse array of potential consumers.

- Research into injectable PrEP, implants, transdermal patches, and long-lasting treatments should be funded as approaches that could significantly increase adherence and efficacy.
- NIH should continue funding research into vaginal and rectal microbicides, which has the potential to eventually transform HIV prevention.
- NIH should continue to support PrEP demonstration projects in the U.S. and globally to understand real-world issues of implementation and best practices, including uptake, adherence, risk compensation, staff training and infrastructure needs. These demonstration projects should include gay men/MSM, transgender women, and other vulnerable populations as participants and community partners in planning to ensure success.
- Demonstration projects should determine the best combination of PrEP with other approaches, such as treatment as prevention, to suit a local context and the unique needs and experiences of vulnerable populations. These findings should be widely disseminated.
- Research is needed on structural HIV prevention interventions, which should be combined with biobehavioral interventions to reduce structural drivers of HIV vulnerability. These could include repeal of laws criminalizing homosexuality (still extant in more than 70 countries, including more than half of PEPFAR countries), passage of nondiscrimination laws covering sexual orientation and gender identity, and public education campaigns challenging anti-gay prejudice and promoting family acceptance of gay sons.

Transgender-specific health needs

- Research has shown transgender women (male to female transgender people) to be at elevated risk of HIV and other STIs.⁵⁴ Transgender women and men are also at risk for substance use, violence victimization, and mental health issues such as depression and suicidal ideation.⁵⁵ Transgender Americans report widespread discrimination and harassment in the workplace and in public settings. Many also report discriminatory and culturally incompetent

⁵⁴ Herbst, J., Jacobs, E., Finlayson, T., McKleroy, V., Neumann, M. and Crepaz, N. (2008) Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. *AIDS Behav* 1(2): 1-17; CDC. HIV among transgender people. <http://www.cdc.gov/hiv/transgender/>. Accessed February 27, 2012. Fenway Institute, HIV Prevalence in Transgender Women. http://www.fenwayhealth.org/site/PageServer?pagename=FCHC_ins_TFINewsletterJuly2011_HIVPreventionTreatment2. Accessed February 27, 2012.

⁵⁵ Kaufman R., Introduction to transgender identity and health. Makadon H, Mayer K, Potter J, & Goldhammer H (eds.). *Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health*. Philadelphia: American College of Physicians. 2008. 331-363.

treatment at the hands of law enforcement and health care providers.⁵⁶

Further research is needed to understand the syndemic of stigma, prejudice and physical and mental health disparities affecting transgender men and women, and how structural interventions can reduce victimization and discrimination and improve health and well-being.

- There are few providers well versed in the unique health care needs of transgender patients, creating a barrier to access to quality care. For example, most transgender women have a prostate and may be candidates for prostate screening if they are high risk (African American, family history of prostate cancer). Transgender men, even those who have had breast reduction surgery, have residual breast tissue that warrants screening for breast cancer with mammography, and many transgender men have a cervix and should be screened for cervical cancer. These screenings should be done with sensitivity to the emotional discomfort they may evoke in transgender patients.⁵⁷ Trainings of providers in transgender health, especially in the prevention screenings described here, should be evaluated to inform the most effective health care approaches.
- While there is a fair amount of research on lesbian, gay and bisexual parenting⁵⁸, there is a dearth of research on transgender parenting. The few preliminary studies have found that children are not negatively affected by their parents' gender identity; in fact, ending parental contact, limiting custody, or requiring a parent to postpone transitioning can all be much more harmful than helpful to the children involved.⁵⁹ More study is needed into the particular experiences, needs and concerns of the children of transgender parents, including experiences related to anti-transgender stigma and prejudice.

A final recommendation regarding the review of NIH proposals on LGBT health research

It may be difficult for researchers to receive favorable scores from scientific review committees (SRC) on LGBT research proposals that are encouraged by NIH, but that may not be perceived as “significant” enough by reviewers due to the size of the LGBT

⁵⁶ Grant, J., Mottet, L., and Tanis, J. *Injustice at every turn: A report of the National Transgender Discrimination Survey*. Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011. http://www.thetaskforce.org/reports_and_research/ntds. Accessed November 15, 2013.

⁵⁷ Feldman J. Medical and surgical management of the transgender patient: What the primary care clinician needs to know. Makadon H, Mayer K, Potter J, & Goldhammer H (eds.). *Ferway Guide to Lesbian, Gay, Bisexual, and Transgender Health*. Philadelphia: American College of Physicians. 2008 372-373.

⁵⁸ Perrin E, Siegel B and the American Academy of Pediatrics, Committee on Psychosocial Aspects of Child and Family Health. Technical report: Promoting the well-being of children whose parents are gay or lesbian. *Pediatrics* 2013;131:e1374.

⁵⁹ Cahill S. & Tobias S. (2007). *Policy issues affecting lesbian, gay, bisexual and transgender families*. University of Michigan Press. 15-16.

population. Similarly, while the NIH acknowledges the need for intervention research to address the health of LGBT people, adapting current interventions to serve LGBT people may not be perceived by SRCs as “innovative” enough to receive fundable scores. Thus, greater education of SRCs about NIH priorities and scoring related to LGBT health and proposals may be warranted. We suggest that SRCs reviewing LGBT health research proposals consider the following:

Significance. Does the project address an important problem or a critical barrier to progress in the field? If the aims of the project are achieved, how will scientific knowledge, technical capability, and/or clinical practice be improved? How will successful completion of the aims change the concepts, methods, technologies, treatments, services, or preventative interventions that drive this field?

Innovation. Does the application challenge and seek to shift current research or clinical practice paradigms by utilizing novel theoretical concepts, approaches or methodologies, instrumentation, or interventions? Are the concepts, approaches or methodologies, instrumentation, or interventions novel to one field of research or novel in a broad sense? Is a refinement, improvement, or new application of theoretical concepts, approaches or methodologies, instrumentation, or interventions proposed?

Thank you for considering these recommendations. Should you have any questions or require more information on any of the suggestions made here, please contact Sean Cahill at the Fenway Institute at scahill@fenwayhealth.org or 617-927-6016.

Sincerely,

Judith Bradford, Ph.D.
Co-chair, Fenway Institute
Director, Center for Population Research in LGBT Health

Kenneth Mayer, M.D.
Co-chair, Fenway Institute
Professor, Harvard Medical School

Stephen Boswell, M.D.
President and CEO
Fenway Health

Sean Cahill, Ph.D.
Director, Health Policy Research
Fenway Institute

Eugenia Handler, M.SW.
Director of Government Relations
Fenway Health

Harvey Makadon, M.D.
Director, National LGBT Health Education Center
Fenway Institute

Clinical Professor of Medicine, Harvard Medical School

Rodney Vanderwarker, M.P.H.

Vice President, Primary Care, Behavioral Health, and Institute Operations
Fenway Health

Aimee Van Wagenen

Director of Administration and Operations
Fenway Institute

Marcy S Gelman, RN, MSN, MPH

Director of Clinical Research and Prevention Programs
Fenway Institute
Fenway Health