

January 24, 2020

Submitted online to SGMRO@nih.gov

RE: Request for Information on the Development of the Fiscal year 2021-2025 Trans-NIH Strategic Plan for Sexual and Gender Minority Health Research

The Fenway Institute thanks the SGMRO for the opportunity to provide comment on the 2021-2025 Trans-NIH Strategic Plan for Sexual and Gender Minority (SGM) Health Research. The Fenway Institute is the research arm of Fenway Health, a federally qualified health center and Ryan White Part C clinic in Boston, MA that serves 32,000 patients each year. About half of our patients are LGBTQIA+, 4,000 are transgender or nonbinary, and 2,200 are people living with HIV. The Fenway Institute works to make life healthier for those who are lesbian, gay, bisexual, and transgender (LGBT), people living with HIV, and the larger community. We do this through research and evaluation, education and training, and policy analysis. We would like to make the following recommendations for the 2021-2025 Trans-NIH Strategic Plan for SGM Research.

Impact of policies and services on SGM health

Policies and services vary significantly across municipalities and states. More and more health organizations have sexual orientation and gender identity (SOGI) nondiscrimination policies, while some states and the federal government have adopted religious refusal policies that could increase anti-LGBT discrimination in health care and restrict access to care. Anti-LGBT discrimination is linked to negative physical and mental health outcomes, and discrimination in health care settings creates barriers to seeking necessary and preventative medical treatment.¹ Many states and cities have adopted targeted services for LGBT elders, LGBT youth, and other populations. Research on the impact of pro- and anti-LGBT policies and of targeted services on health and well-being is needed. What policies and targeted services correlate with greater resiliency, health and well-being? Do health care entities need technical support to implement anti-discrimination policies?

SGM older adults

Research to evaluate the effectiveness of group-level and community-level interventions to promote community and reduce social isolation among LGBT older adults is needed especially with programs and interventions that receive funding through the Older Americans Act. Social isolation is of particular concern for LGBT elders because they are less likely to have children and more likely to live alone compared to their heterosexual peers.² Furthermore, LGBT elders may be afraid to access mainstream elder services due to fear of discrimination, and this can exacerbate social isolation. Interventions to promote community and reduce social isolation

¹ Lambda Legal. (2010.) *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal.

² Fredriksen-Goldsen KI, Kim HJ, Emlet CA, Muraco A, Erosheva EA, Hoy-Ellis CP, ...Petry, H. (2011). *The aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults*. Seattle: University of Washington, Institute for Multigenerational Health.

include congregate meal programs, LGBT elder bereavement groups, LGBT-friendly congregate housing, and other interventions.

More research is necessary to study the experiences of LGBT elders and older adults living with HIV in senior service settings, where age peers are more likely than other age cohorts to hold homophobic views and to be misinformed about how HIV is transmitted. This research could inform interventions, changes to services, and best practices to ensure that they can access elder services.

Research on transgender elders is especially needed. Transgender elders can experience family rejection from children and rejection from LGB community members. They often experience culturally incompetent care from elder service and care providers.³

Lesbian and bisexual women's health

There is a dearth of research on the health issues affecting lesbian and bisexual women. We need more disparities research and intervention research in chronic disease among sexual minority women, including cardiovascular health, stroke, functional impairments, BMI, asthma, cancer—including colorectal and lung cancer. Sexual minority women often report high prevalence of stigma and discrimination resulting in higher rates of depression and other behavioral health disparities, with bisexual women reporting higher rates than both their lesbian and heterosexual counterparts.⁴ We encourage the SGMRO to provide more explicit information about how SGM research funding at NIH is allotted to various populations, including sexual minority women, Black LGBT people, migrant LGBT people, Native American LGBT and other LGBT populations.

SGM prisoners and youth in juvenile justice systems

LGBT people are overrepresented in adult prisons and jails and youth systems. One in twenty (4.5%) of U.S. adults identifies as LGBT,⁵ while 9.3% of men in prison and 42.1% of women in prison identify as sexual minorities.⁶ LGBT people who are incarcerated experience much higher rates of sexual victimization and violence victimization than heterosexual, cisgender incarcerated.⁷ The Prison Rape Elimination Act is being implemented to reduce this disparity and end prison rape, yet we have anecdotal evidence from formerly incarcerated LGBT people that

³ Cahill S. (2017). Research and policy change to improve health care and elder services for LGBT older adults. *LGBT Health*. 4(6): 381-383.

⁴ Bostwick W. (2012, May 18). Assessing Bisexual Stigma and Mental Health Status: A Brief Report. *Journal of Bisexuality*. 12(2): 214-222.

⁵ Newport F (2018). In U.S., estimate of LGBT population rises to 4.5%. Gallup News. <https://news.gallup.com/poll/234863/estimate-lgbt-population-rises.aspx>

⁶ Meyer I, Flores A, Stemple L et al. (2017). "Incarceration Rates and Traits of Sexual Minorities in the United States: National Inmate Survey, 2011–2012." *Am J Public Health*. 107(2):234–240. The data that Meyer et al. analyze is from: Beck AJ, Berzofsky M and Krebs C (2013). Sexual Victimization in Prisons and Jails Reported by Inmates, 2011–12 National Inmate Survey, 2011–2012. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics <https://www.bjs.gov/content/pub/pdf/svpjri1112.pdf>

⁷ Beck AJ and Johnson C (2012). Sexual victimization reported by former state prisoners, 2008. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. <http://www.bjs.gov/content/pub/pdf/svrfsp08.pdf>

PREA is being misused to single out and hyperpolice LGBT people's behavior, often resulting in their being sent to solitary confinement for no legitimate reason. Collection of SOGI data within corrections and juvenile justice systems and research on the experiences of LGBT people in corrections and juvenile justice settings is needed.

Long-term survivors with HIV and older adults living with HIV

NIH should fund large-scale, national, longitudinal studies that investigate how antiretroviral medications and HIV disease interact with aging bodies, and how they interact with treatments for comorbidities such as high cholesterol medication. Additional areas of research that should be pursued include: the extent to which the normal aging processes are accelerated as a result from viral infection and immune activation from long-term HIV treatment; the incidence and determinants of cognitive decline in aging HIV-positive individuals; and social interventions to improve behavioral health and reduce isolation among long-term survivors with HIV.

SGM youth

Research is needed on how best to promote parent-child conversations about sexual health and healthy dating, HIV/STI/pregnancy prevention, and SGM identity formation and support. Lack of knowledge about safer sex strategies—for example, use of lubricants with condoms—and concerns about being outed are common barriers to accessing sexual health services for SGM youth. SGM youth also experience barriers to sexual health care common to youth in that age group, such as cost and embarrassment, and that barriers HIV screening, such as fear of getting an HIV diagnosis and the perceived exorbitant cost of treating HIV. HIV prevention and comprehensive education interventions involving both youth and parents that address these concerns are needed.

Many SGM youth, especially gay and bisexual males and transgender youth, also experience self-esteem, body image, and disordered eating issues. Low self-esteem can make it more difficult to navigate sexual situations and advocate for safer sex strategies with potential partners. In the case of transgender youth, dysphoria can also play a major role in sexual encounters. Research to develop interventions to improve self-esteem and self-advocacy, especially in terms of sexual communication, is needed.

Most youth cannot access school-based sexual health education that is inclusive of same-sex behavior and LGBT experiences. Adults serving youth, such as school nurses and adolescent health providers, can play a key role in health education. Youth also want age peers to deliver sexual health messages. Research is needed to inform and evaluate best practices for promoting sexual health education, especially in rural and socially conservative districts. NIH should also support research to develop innovative ways to reach youth using social media and technology with LGBT-inclusive sexual health information.⁸

⁸ This section is based on research that Fenway has conducted with the Centers for Disease Control Division of Adolescent and School Health and with NORC at the University of Chicago. Two articles in press are: Fontenot HB, Cahill SR, Wang T, et al. (in press). Transgender youth's experiences and perspectives related to HIV preventive services. *Pediatrics*; Cahill SR, Geffen S, Fontenot HB, et al. (in press). Youth-serving professionals' perspectives on HIV prevention tools and strategies appropriate for adolescent gay and bisexual males and transgender youth.

Intervention research to promote resiliency through Positive Youth Development, family acceptance and other approaches is needed.

Fund a research network of community health centers and research hospitals to track an ongoing clinical cohort of SGM patients

This could be similar to the CFAR Network of Integrated Clinical Systems (CNICS) Research Network. It could allow us to better understand LGBT health disparities, health care needs, and inform improvements to care.

Studies of interventions to enhance clinician ability to provide culturally competent care for SGM patients

LGBT people face widespread discrimination in health care, such as being verbally or physically harassed or being denied treatment altogether.⁹ This discrimination acts as a barrier to seeking necessary routine, preventive care as well as emergency care. For example, the 2015 U.S. Transgender Survey of nearly 28,000 transgender people found that in the last year, 33% of respondents had experienced anti-transgender discrimination in health care, and 23% of respondents chose to forego necessary health care due to fear of discrimination.¹⁰ A 2018 survey by the Center for American Progress found that 14% of LGBT respondents who had previously experienced discrimination in health care avoided seeking necessary medical care, and 17% avoided seeking preventive care in the past year.¹¹ As such, it is critical to evaluate interventions that are meant to enhance clinician ability to provide culturally competent care for SGM patients. Effective interventions should be disseminated widely in order to create more welcoming and affirmative clinical spaces for SGM individuals across the country.

SGM people with disabilities

We need more research on differently abled LGBT people, including LGBT people with intellectual disabilities and those who are deaf or blind. The SGMRO should encourage the Administration for Community Living to add SOGI questions to Centers for Independent Living Annual Program Performance Report, as was originally planned for 2017 but then subsequently removed. Research has shown that there is higher prevalence of disability among SGM populations. For example, one study of 2003, 2005, 2007, and 2009 BRFSS data found higher prevalence of disability among LGB adults compared with their heterosexual counterparts that remained significant after controlling for various covariates of disability.¹²

Journal of Pediatric Health Care. Recommendations here are those of the Fenway Institute alone and not those of CDC DASH or NORC.

⁹ Lambda Legal. (2010.) *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal.

¹⁰ James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality.

¹¹ Mirza S and Rooney C. (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress.

¹² Fredriksen-Goldsen K, Kim H, Barkan S. (2012 January). Disability Among Lesbian, Gay, and Bisexual Adults: Disparities in Prevalence and Risk. *American Journal of Public Health*. 102(1): e16-e21.

Vaping

Vaping is a potentially dangerous newer phenomenon that requires more research in general. Research has shown that the prevalence of e-cigarette use is high among LGBT people, especially among younger LGBT people.¹³ Research on use of tobacco and non-tobacco products is needed. Research is needed to develop prevention and cessation interventions specifically targeted towards LGBT people, drawing from and building upon the mixed experience with LGBT-targeted smoking cessation interventions.

We thank you for the opportunity to provide comment. If you have any feedback or questions, feel free to reach out to Sean Cahill, Director of Health Policy Research at scahill@fenwayhealth.org.

Sincerely,

Jane Powers, MSW, LICSW
Acting Chief Executive Officer
Fenway Health

Jennifer Potter, MD
Co-Chair and LGBT Population Health Program Director
The Fenway Institute

Carl Sciortino, MPA
Vice President of Government and Community relations
Fenway Health

Sean Cahill, PhD
Director of Health Policy Research
The Fenway Institute

Tim Wang, MPH
Senior Policy Analyst
The Fenway Institute

Peter Chai, MD, MMS
Department of Emergency Medicine, Brigham and Women's Hospital
Department of Psychosocial Oncology and Palliative Care, Dana Farber Cancer Institute
Assistant Professor of Emergency Medicine, Harvard Medical School
Affiliate Research Scholar, The Koch Institute for Integrated Cancer Research
Adjunct Faculty, The Fenway Institute

¹³ Mirbolouk M, Charckhchi P, Kianoush S, et al. (2018, October 2). Prevalence and Distribution of E-Cigarette Use Among U.S. Adults: Behavioral Risk Factor Surveillance System, 2016. *Annals of Internal Medicine*. 169(7): 429-438.

Douglas Krakower, MD
Division of Infectious Diseases, Beth Israel Deaconess Medical Center
Department of Population Medicine, Harvard Medical School
The Fenway Institute, Fenway Health

Debbie Ojeda-Leitner, PhD
Policy Advocate
National Center for Transgender Equality

Harper Jean Tobin, JD, MSSA
Director of Policy
National Center for Transgender Equality

Mara Keisling
Executive Director
National Center for Transgender Equality