

November 27, 2017

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

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

**FACULTY**

Kevin L. Ard, MD  
Adjunct Faculty

Abigail Batchelder, PhD, MPH  
Affiliated Investigator

Katie B. Biello, PhD  
Research Scientist

Aaron J. Blashill, PhD  
Affiliated Investigator

Stephen Boswell, MD  
Senior Research Scientist

Wendy Bostwick, PhD, MPH  
Adjunct Faculty

Sean Cahill, PhD  
Director of Health Policy  
Research

Kerith J. Conron, ScD, MPH  
Research Scientist

Brian Dodge, PhD  
Adjunct Faculty

Holly Fontenot, PhD, RN,  
WHNP-BC  
Adjunct Faculty

Alex Keuroghlian, MD, MPH  
Director, Education & Training  
Programs

Douglas S. Krakower, MD  
Adjunct Faculty

Lisa Krinsky, LICSW  
Director of the LGBT Aging  
Project

Matthew Mimiaga, ScD, MPH  
Senior Research Scientist

Conall O'Cleirigh, PhD  
Affiliated Investigator

Bisola Ojikutu, MD, PhD  
Adjunct Faculty

David W. Pantalone, PhD  
Behavioral Scientist

Jennifer Putney, MSW, PhD  
Adjunct Faculty

Sari L. Reisner, ScD  
Research Scientist

Steve Safren, PhD  
Affiliated Investigator

S. Wade Taylor, PhD  
Associate Research Scientist

Marcy Gelman, RN, MSN, MPH  
Director of Clinical Research

Bonnie McFarlane, MPP Director  
of Administration

U.S. Department of Health and Human Services  
Administration for Community Living  
Washington, DC 20201  
Attention: Heather Menne

**RE:** Agency Information Collection Activities; Public Comment Request;  
Redesign of Existing Data Collection; National Survey of Older Americans Act  
Participants

Dear Dr. Menne,

The Fenway Institute submits this public comment in response to the notice posted by the Administration for Community Living (ACL) on September 26, 2017 titled, Agency Information Collection Activities; Public Comment Request; Redesign of Existing Data Collection; National Survey of Older American Act Participants. Switching the National Survey of Older American Act Participants (NSOAAP) to a longitudinal format rather than a cross-sectional format could provide valuable data on tracking disparities in health outcomes and service utilization among elders over time. This could be a very useful tool for addressing the disparities that exist within specific elder populations, including lesbian, gay, bisexual, and transgender (LGBT) elders. As such, it is important that the redesigned NSOAAP ask about sexual orientation and gender identity (SOGI) in order to ensure that the specific needs of LGBT elders across the country are being met and that LGBT older adults are accessing elder services.

Collecting data on LGBT older adults and the extent to which they access elder services is critically important for reducing the health disparities that this population experiences. Studies have shown that LGBT older adults are more likely to report being physically disabled or have poor mental health outcomes compared to the general population.<sup>1</sup> LGBT elders are also more likely to be isolated than their peers.<sup>2</sup> As such, many LGBT older adults may be in need of elder services. However, research indicates that they may be less likely to access formal caregiving support and other elder services.<sup>3</sup> In general, older Americans are more likely to hold anti-gay views than younger age cohorts,<sup>4</sup> and they are

---

<sup>1</sup> Fredriksen-Goldsen, K.I., H.J. Kim, C. Emlet et al. 2011. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual and Transgender Older Adults*. Seattle, WA: Institute for Multigenerational Health.

<sup>2</sup> MetLife Mature Market Institute and American Society on Aging. 2010. *Still Out, Still Aging: The MetLife Study of Lesbian, Gay, Bisexual and Transgender Baby Boomers*. Westport, CT: MetLife. <http://www.lgbtagingcenter.org/resources/pdfs/StillOutStillAging.pdf>

<sup>3</sup> U.S. Administration on Aging. 2001. Fact sheet: The many faces of aging. Washington, DC.

<sup>4</sup> Anderson, R., Fetner, T. 2008. "Cohort Differences in Tolerance of Homosexuality: Attitudinal Change in Canada and the United States, 1981-2000." *Public Opinion Quarterly* 72(2): 311-330.

also more likely to hold inaccurate beliefs about the casual transmission of HIV.<sup>5</sup> These both can contribute to creating a more hostile environment toward LGBT older adults in mainstream elder service facilities.

We are pleased to see that the demographic question regarding sexual orientation is retained in the proposed redesign of the NSOAAP. We also support the addition of the unique topical modules to collect additional information about experiences with discrimination related to sexual orientation. Experiences of discrimination or anticipation of discrimination based on negative experiences of friends in mainstream elder service settings causes many sexual minority elders to choose not to seek the support services they need to age in place and thrive in older adulthood.<sup>6</sup> Asking questions about discrimination based on sexual orientation is important for addressing these barriers to elder services for sexual minority elders.

We are disappointed that the gender identity question was not added back in for the proposed redesign of the NSOAAP. We recommend that the ACL add a gender identity demographic question to the proposed NSOAAP, and we also propose that the ACL add a question regarding discrimination based on gender identity to the topical modules. In general, research has shown that transgender people experience high rates of economic instability, disability, and mental health burden. The 2015 United States Transgender survey of nearly 28,000 transgender respondents found that nearly one third of participants (29%) were living in poverty, which is twice the rate of the general population. The survey also found that 39% of respondents had one or more disabilities as described by the American Community Survey, compared to 15% of the general population. Furthermore, 39% of respondents reported experiencing serious psychological distress in the month prior to completing the survey, compared to 5% of the general population. Some 40% of respondents had attempted suicide in their lifetime. Respondents also indicated that they commonly experienced discrimination in accessing healthcare services, with 33% of respondents reporting at least one negative experience, such as being verbally harassed or refused treatment.<sup>7</sup> Due to the high rates of disability and mental health burden, transgender older adults may be in greater need of elder services, but they may forego accessing these services due to past experiences of discrimination.

In order to better understand the needs and experiences of older LGBT adults, and especially the needs of older transgender adults, it is critical to collect population-level SOGI data. SOGI questions are now included in many public health surveys, such as the Behavioral Risk Factor Surveillance System. While we are pleased that the sexual orientation question is included in the proposed 2017 NSOAAP, in order to better understand the needs and improve the health

---

<sup>5</sup> 2012 Survey of Americans on HIV/AIDS. Washington, DC: Kaiser Family Foundation; 2012. Available at: <http://www.kff.org/hiv/aids/poll-finding/2012-survey-of-americans-on-hiv/aids/>

<sup>6</sup> Stein G, Beckerman N, Sherman P. 2010. Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. *J Gerontol Soc Work.* 2010;53(5):421-35.

<sup>7</sup> James, S. E., Herman, J. L., 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.

and well-being of older transgender adults, it is critical that a transgender status or other gender identity question be added to the proposed redesign of the NSOAAP. We encourage the ACL to consider adding a two-step question, first asking current gender identity, and then asking for sex assigned at birth.<sup>8</sup> It could also use the transgender question asked on many state BRFSS surveys.<sup>9</sup>

Some may say that the gender identity question should be removed due to the small number of older adults who identify as transgender. We do not believe this is a legitimate reason to remove this question, as other surveys of older Americans have also found lower percentages of participants who identified as transgender. The small number of older adults who identified as transgender on the NSOAAP is in line with the small number of people who identify as transgender in the general population. A Williams Institute analysis of state Behavioral Risk Factor Surveillance System surveys found that 0.58% of Americans aged 18 and older, or 1.4 million people, identify as transgender.<sup>10</sup> In addition, often response rates to sexual orientation and gender identity (SOGI) questions are low when new questions are first added to a survey. Furthermore, transgender elders can be purposefully oversampled in anticipation of a small sample size, or multiple years of data can be aggregated. It is essential that ACL follow the growing consensus among federal agencies and professional health organizations that SOGI data should be collected to better understand LGBT people's experiences in elder services and other settings. We commend the ACL for keeping the sexual orientation questions for the proposed NSOAPP, and we urge the ACL to add in a gender identity question.

Sincerely,

Stephen L. Boswell, MD, FACP  
President and Chief Executive Officer  
Fenway Health

Kenneth Mayer, MD, FACP  
Co-chair and Medical Research Director, The Fenway Institute  
Director of HIV Prevention Research, Beth Israel Deaconess Medical Center  
Professor of Medicine, Harvard Medical School

Jennifer Potter, MD  
Co-chair, The Fenway Institute  
Director of Women's Health, Fenway Health

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

---

<sup>8</sup> Cahill S, Makadon H, Baker K. 2014. *Do Ask, Do Tell: A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings*. Boston: Fenway Institute, Center for American Progress

<sup>9</sup> Centers for Disease Control and Prevention. 2014. 2014 Behavioral Risk Factor Surveillance System Questionnaire. [https://www.cdc.gov/brfss/questionnaires/pdf-ques/2014\\_brfss.pdf](https://www.cdc.gov/brfss/questionnaires/pdf-ques/2014_brfss.pdf)

<sup>10</sup> Flores, A., Herman, J., Gates, G., Brown, T. 2016. *How many adults identify as transgender in the United States?* Los Angeles: The Williams Institute at UCLA School of Law. Available at: <https://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf>

Lisa Krinsky, MSW, LICSW  
Director, LGBT Aging Project, The Fenway Institute

Tim Wang, MPH  
Health Policy Analyst, The Fenway Institute