

December 21, 2023

Submitted to: Katherine.Glendenning@acl.hhs.gov

Administration for Community Living  
330 C Street SW  
Washington, DC 20201

Attention: Katherine Glendenning

RE: [Federal Register :: Agency Information Collection Activities; Proposed Collection; Comment Request; Alzheimer's and Dementia Program Data Reporting Tool \(ADP-DRT\) OMB Control Number 0985-0022](#)

The Fenway Institute at Fenway Health appreciates the opportunity to submit the following comment regarding the Administration for Community Living's proposed rule on the addition of SOGI (sexual orientation and gender identity) questions to the Alzheimer's and Dementia Program Data Reporting Tool.

The Fenway Institute is the research, policy, education, and training arm of Fenway Health, a federally qualified health center and Ryan White Part C HIV clinic in Boston, Massachusetts. We provide care to about 35,000 patients every year. Half of our patients identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual, or another identity (LGBTQIA+), and about 6,000 are transgender and nonbinary. About 2,700 of our patients are people living with HIV (PLWH), and we have about 3,500 patients on PrEP for HIV prevention, and more than 1,000 on doxyPEP for STI prevention. A main focus of our work is providing healthcare for sexual and gender diverse people, as well as HIV and STI prevention and research.

As a Federally Qualified Health Center and Ryan White Part C HIV clinic that serves the needs of older LGBTQIA+ individuals and older PLWH, and as the home of the LGBTQIA+ Aging Project, which provides trainings, advocacy, and services to improve the lives of these two intersecting populations, we express our overall support for the proposed addition of SOGI (sexual orientation and gender identity) questions to the Alzheimer's and Dementia Program Data Reporting Tool. This progressive step towards inclusivity will enable critically important data to be collected on LGBTQIA+ older adults. This will inform targeted support for populations facing unique challenges, experiences, and health disparities.

We respond below to each of the listed requests from the ACL. Please note that LGBT, LGBTQ, LGBTQIA+, LGBTQI+ acronyms are used throughout this document, depending on the source of the data we are citing.

- (1) Whether the proposed collection of information is necessary for the proper performance of ACL's functions, including whether the information will have practical utility

LGBT older adults have higher rates of risk factors for dementia.<sup>1</sup> Transgender veterans are more likely than cisgender veterans to have Alzheimer's.<sup>2</sup> Smoking rates are elevated among older people living with HIV (PLWH),<sup>3</sup> as are other substance use disorders; this contributes to neurocognitive decline.<sup>4</sup> Loneliness among PLWH correlates with anxiety, depression, recent alcohol consumption, and higher daily cigarette smoking. Stanton et al. state that "loneliness is a likely contributor to the ongoing smoking epidemic among people with HIV."<sup>5</sup> Neurocognitive decline can make it difficult for older PLWH to maintain satisfactory job performance, contributing to early retirement. This leads to loss of social support in the workplace and poverty.

Older LGBT people experience greater physical and mental health disparities compared with their heterosexual, cisgender age peers.<sup>6</sup> These include higher rates of kidney disease among LGB and other individuals age 50 or older compared to heterosexual age peers.<sup>7</sup> LGBT people also experience higher rates of chronic conditions such as diabetes,<sup>8</sup> asthma,<sup>9</sup> obesity, and cardiovascular disease,<sup>10</sup> and higher rates of certain cancers,<sup>11</sup> cancer risk factors, and access to preventive screenings and care.<sup>12</sup> LGBT people also experience higher rates of alcohol and

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<sup>1</sup> Nowaskie DZ, Sewell DD. Assessing the LGBT cultural competency of dementia care providers. *Alzheimers Dement (N Y)*. 2021;7(1):e12137. Published 2021 Feb 14. doi:10.1002/trc2.12137. Please note that LGBT, LGBTQ, LGBTQIA+, LGBTQI+ acronyms are used throughout this document, depending on the source of the data we are citing.

<sup>2</sup> Jasuja GK, Reisman JI, Rao SR, et al. Social Stressors and Health Among Older Transgender and Gender Diverse Veterans. *LGBT Health*. 2023;10(2):148-157. doi:10.1089/lgbt.2022.0012.

<sup>3</sup> Melanie A Thompson, Michael A Horberg, Allison L Agwu, Jonathan A Colasanti, Mamta K Jain, William R Short, Tulika Singh, Judith A Aberg, Primary Care Guidance for Persons With Human Immunodeficiency Virus: 2020 Update by the HIV Medicine Association of the Infectious Diseases Society of America, *Clinical Infectious Diseases*, Volume 73, Issue 11, 1 December 2021, Pages e3572–e3605, <https://www.idsociety.org/practice-guideline/primary-care-management-of-people-with-hiv/>

<sup>4</sup> National HIV Curriculum, Key Populations, Lesson 4, HIV in Older Adults, Topic 6: Common Comorbid Conditions in Older Persons with HIV. <https://www.hiv.uw.edu/custom/key-populations/hiv-older-patients/6>

<sup>5</sup> Stanton CA, Moadel AB, Kim RS, et al. Loneliness in HIV-infected smokers. *AIDS Care*. 2015;27(2):268-272.

<sup>6</sup> Kimmel D. Lesbian, Gay, Bisexual, and Transgender Aging Concerns. *Clin. Gerontol*. 2014;37:49–63.

<sup>7</sup> Chandra M, Hertel M, Cahill S, Sakaguchi K, Khanna S, Mitra S, Luke J, Khau M, Mirabella J, Cropper A. Prevalence of Self-Reported Kidney Disease in Older Adults by Sexual Orientation: Behavioral Risk Factor Surveillance System Analysis (2014-2019). *J Am Soc Nephrol*. 2023 Apr 1;34(4):682-693.

<sup>8</sup> Beach LB, Elasy TA, Gonzales G. Prevalence of Self-Reported Diabetes by Sexual Orientation: Results from the 2014 Behavioral Risk Factor Surveillance System. *LGBT Health*. 2018 Feb/Mar;5(2):121-130.

<sup>9</sup> Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, Chengshi Shui, and Amanda E. B. Bryan, 2017: [Chronic Health Conditions and Key Health Indicators Among Lesbian, Gay, and Bisexual Older US Adults, 2013–2014](https://doi.org/10.1186/s12874-017-0338-1). *American Journal of Public Health* 107, 1332\_1338.

<sup>10</sup> Fredriksen-Goldsen KI, Kim H-J, Emlert CA, et al. *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle: University of Washington; 2011.

<sup>11</sup> Cathcart-Rake EJ. Cancer in Sexual and Gender Minority Patients: Are We Addressing Their Needs? *Curr Oncol Rep*. 2018 Sep 13;20(11):85.

<sup>12</sup> Wakefield D. Cancer care disparities in the LGBT community. *Curr Opin Support Palliat Care*. 2021 Sep 1;15(3):174-179.

substance use.<sup>13,14</sup> Many of these chronic conditions and health behaviors are risk factors for Alzheimer's and dementia.<sup>15</sup>

Collecting SOGI data in the Alzheimer's and Dementia Program Data Reporting Tool will allow us to better understand elevated risk for these conditions in sexual and gender minority communities, and how this risk intersects with risk and disparities along lines of race and ethnicity and other demographic factors. Given high rates of medical mistrust among older LGBTQIA+ people,<sup>16</sup> the collection of these data will allow us to understand whether people are accessing services at a rate proportional to their share of the population. The collection of these data can also enhance our understanding of any disparities in preventive screenings and enable clinical decision support and population health management.

(2) Ways to enhance the quality, utility, and clarity of the information to be collected;

The Fenway Institute believes that ACL should consider adding a sex characteristics question to measure intersex status, or differences in sexual development. The Fenway Institute encourages ACL to work with LGBTQIA+ stakeholders, the intersex community and its leading organization interACT: Advocates for Intersex Youth to develop questions and response options that reflect the categories used by intersex people to describe themselves. Researchers at the Fenway Institute are examining the best ways to ask patients about sex characteristics, working closely with intersex community leaders. We encourage ACL to connect with intersex leaders and researchers to help develop a culturally competent sex characteristics question and response options to document and better serve members of the intersex community.

(3) Accuracy of ACL's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used to determine burden estimates;

We believe that ACL has accurately estimated the burden of the proposed collection of information. The inclusion of SOGI questions comes with relatively minimal burden and the expected benefits far outweigh the cost.

(4) Ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques when appropriate, and other forms of information technology.

In our experience with collecting SOGI data in health care settings, we have found that patients feel greater anonymity when filling out a survey online than on paper. Research has shown that

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<sup>13</sup> Phillips Ii G, Turner B, Felt D, Han Y, Marro R, Beach LB. Trends in Alcohol Use Behaviors by Sexual Identity and Behavior Among High School Students, 2007-2017. *J Adolesc Health*. 2019;65(6):760-768. doi:10.1016/j.jadohealth.2019.06.007.

<sup>14</sup> Connolly DJ, Davies E, Lynskey M, et al. Differences in Alcohol and Other Drug Use and Dependence Between Transgender and Cisgender Participants from the 2018 Global Drug Survey. *LGBT Health*. 2022;9(8):534-542. doi:10.1089/lgbt.2021.0242.

<sup>15</sup> Omura JD, McGuire LC, Patel R, et al. Modifiable risk factors for Alzheimer disease and related dementias among adults aged ≥ 45 years—United States, 2019. *MMWR Morb Mortal Wkly Rep*. 2022;71:680–685. DOI: <http://dx.doi.org/10.15585/mmwr.mm7120a2>.

<sup>16</sup> Stinchcombe A, Smallbone J, Wilson K, Kortess-Miller K. Healthcare and End-of-Life Needs of Lesbian, Gay, Bisexual, and Transgender (LGBT) Older Adults: A Scoping Review. *Geriatrics (Basel)*. 2017;2(1):13. Published 2017 Mar 16. doi:10.3390/geriatrics2010013.

automated collection of sexual orientation data and other sensitive data yields higher rates of people identifying as sexual minority or answering other sensitive questions.<sup>17,18</sup> Using computers or tablets has the additional benefit of requiring less time and ensuring greater protection of data given appropriate encryption/storing methods. However, surveys must also be offered in paper form for those that are unfamiliar with operating a computer or tablet.

Thank you for the opportunity to comment on the Administration for Community Living's proposed rule on the addition of SOGI (sexual orientation and gender identity) questions to the Alzheimer's and Dementia Program Data Reporting Tool. This proposed rule represents an essential step towards addressing cognitive health disparities faced by older LGBTQIA+ people, including many older people living with HIV. Through the implementation of these changes, we can work towards a more equitable and inclusive health care and older adult care system that meets the diverse needs of our aging population. Should you have any questions about this comment, please contact Sean Cahill, PhD, Director of Health Policy Research at The Fenway Institute, at [scahill@fenwayhealth.org](mailto:scahill@fenwayhealth.org)

Sincerely,

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<sup>17</sup> Villarroel M.A., C.F. Turner, E. Eggleston et al. 2006. "Same-Gender Sex in the United States: Impact of T-ACASI on Prevalence Estimates." *Public Opinion Quarterly* 70(2):166–96. doi:10.1093/poq/nfj023.

<sup>18</sup> Crane H.M., W. Lober, E. Webster et al. 2007. "Routine Collection of Patient-Reported Outcomes in an HIV Clinical Setting: The First 100 patients." *Current HIV Research* 5:109–18. doi:10.2174/157016207779316369.

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