

December 21, 2023

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

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

Attention: Katherine Glendinging

RE: [Federal Register :: Agency Information Collection Activities; Proposed Collection; Comment Request; State Health Insurance Assistance Program \(SHIP\) Client Contact Forms OMB Control Number 0985-0040](#)

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 on State Health Insurance Assistance Program (SHIP) Client Contact Forms.

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 5,400 are transgender and nonbinary. About 2,300 of our patients are people living with HIV (PLWH). 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 questions on State Health Insurance Assistance Program (SHIP) Client Contact Forms. 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

Older LGBT people experience greater physical and mental health disparities compared with their heterosexual, cisgender age peers.¹ These include higher rates of kidney disease among LGB and other individuals age 50 or older compared to heterosexual age peers.² LGBT people also experience higher rates of chronic conditions such as diabetes,³ asthma,⁴ obesity, and cardiovascular disease,⁵ and higher rates of certain cancers,⁶ cancer risk factors, and access to preventive screenings and care.⁷ LGBT people with disabilities experience disparities in health status when compared to straight, cisgender peers.⁸

Many older LGBTQIA+ people need the help of the State Health Insurance Assistance Program to access Medicare and supplemental insurance when they reach retirement age.

In Massachusetts, in 2019 and 2020, The Fenway Institute worked with colleagues at the Mass. Department of Public Health to analyze Behavioral Risk Factor Surveillance System Survey data for older LGBTQIA+ people. We also conducted 9 in-person and virtual listening sessions with LGBTQIA+ older adults across Massachusetts. Among our key findings were the following:

- The need for help accessing Medicare, especially for people living with HIV who are on Medicaid as they approach age 65
- Strong anti-LGBTQIA+ prejudice in rural Massachusetts, and from age peers across the Commonwealth
- Social isolation and lack of connection
- Mental health needs specific to social isolation
- The need for ongoing services and mental health care for LGBTQIA+ widows and widowers, especially those on Cape Cod and in other rural areas
- The need for social activities that create a sense of community and belonging
- Anti-LGBTQIA+ discrimination in assisted living
- Anti-gay harassment in businesses and health care facilities in the Berkshires
- The centrality of trauma in people's lives

¹ Kimmel D. Lesbian, Gay, Bisexual, and Transgender Aging Concerns. *Clin. Gerontol.* 2014;37:49–63. Please note that LGBT, LGBTQ, LGBTQIA+, LGBTQI+ acronyms are used throughout this document, depending on the source of the data we are citing.

² 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.

³ 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.

⁴ 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.](#) *American Journal of Public Health* 107, 1332_1338.

⁵ Fredriksen-Goldsen KI, Kim H-J, Emler CA, et al. *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults.* Seattle: University of Washington; 2011.

⁶ Cathcart-Rake EJ. Cancer in Sexual and Gender Minority Patients: Are We Addressing Their Needs? *Curr Oncol Rep.* 2018 Sep 13;20(11):85.

⁷ Wakefield D. Cancer care disparities in the LGBT community. *Curr Opin Support Palliat Care.* 2021 Sep 1;15(3):174-179.

⁸ Streed CG Jr, Hall JP, Boyd BA, Batza K, Kurth NK. Comparative Health Status and Characteristics of Respondents of the 2019-2020 National Survey on Health and Disability by Sexual and Gender Minority Status. *LGBT Health.* 2021;8(8):563-568. doi:10.1089/lgbt.2021.0075.

- The need to address racism within the LGBTQIA+ community
- A dearth of LGBTQIA+ competent and affirming health care in rural Massachusetts
- Struggling to pay for health care
- Economic hardship in general

Working with Maria McKenna, Director of the Office of Data Management and Outcomes Assessment at the Massachusetts Department of Public Health, we analyzed Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) survey data, which showed the following statistically significant differences between LGBT people age 50-75 and straight, cisgender people 50-75:

- LGBT elders reported higher rates of fair/poor overall health, and
- Were nearly twice as likely to report ever having been diagnosed with a depressive disorder
- Were more likely to rent and less likely to own their home
- Were nearly three times as likely to report difficulty paying for housing or food in past year
- Were more likely to report serious difficulty concentrating, remembering or making decisions
- Were near twice as likely to fall and be injured in a fall in the past year
- Reported four times the rate of suicidal thoughts in past year
- Reported three times the rate of lifetime sexual violence victimization
- Lesbian and bisexual women were more likely to be obese and less likely to be of normal weight than heterosexual women in Massachusetts.⁹

Partly because of widespread societal discrimination, LGBT people are more likely than heterosexual, cisgender people to live in poverty, with transgender people, bisexuals, and people of color experiencing the highest rates of poverty within the LGBT community.¹⁰ There is evidence that LGBT people experience disproportionate economic hardship. The U.S. Census Bureau's Household Pulse survey found that, during the first year and a half of the COVID-19 pandemic, LGBT people experienced twice the rate of food insecurity (14% vs. 7%), higher job loss, and twice the rate of depression and anxiety as straight and cisgender people.¹¹

All these findings have significant implications for elder services and health care for LGBTQIA+ older adults. The collection of SOGI data is the necessary first step in ensuring that LGBTQIA+ individuals have their diverse health needs met. The collection of this information has utility in ensuring that older members of the LGBTQIA+ community, who

⁹ Cahill S (2020). *LGBT Aging 2025: Strategies for Achieving a Healthy and Thriving LGBT Older Adult Community in Massachusetts*. Boston: The Fenway Institute, LGBT Aging Project. <https://fenwayhealth.org/wp-content/uploads/LGBT-Aging-2025-Report-December-2020.pdf>

¹⁰ Badgett L, Choi S, Wilson B. *LGBT Poverty in the United States: A study of differences between sexual orientation and gender identity groups*. UCLA School of Law: The Williams Institute, 2019. Available at: <https://williamsinstitute.law.ucla.edu/publications/lgbt-poverty-us/> Accessed January 11, 2022.

¹¹ File T, Marshall J. Household Pulse Survey Shows LGBT Adults More Likely to Report Living in Households With Food and Economic Insecurity Than Non-LGBT Respondents. U.S. Census Bureau. August 11, 2021. Available at <https://www.census.gov/library/stories/2021/08/lgbt-community-harder-hit-by-economic-impact-of-pandemic.html> Accessed September 7, 2023.

experience disproportionate negative health outcomes, can be connected with the appropriate services. This collection of information is critical in achieving health justice for marginalized individuals in Massachusetts and across the U.S.

(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 using 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 automated collection of sexual orientation data and other sensitive data yields higher rates of people identifying as sexual minority or answering other sensitive questions.^{12,13} 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 on State Health Insurance Assistance Program (SHIP) Client Contact Forms. This proposed rule represents an essential step towards addressing the disparities faced by older LGBTQIA+ people. Through the implementation of these changes, we can work towards a more equitable and inclusive elder services and care system that meets the diverse needs of our aging

¹² 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.

¹³ 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.

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

Sincerely,

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