

September 9, 2019

Center for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-1711-P
P.O. Box 8013
Baltimore, MD 1244-8013

RE: Medicare and Medicaid Programs; CY 2020 Home Health Prospective Payment System Rate Update; Home Health Value-Based Purchasing Model; Home Health Quality Reporting Requirements; and Home Infusion Therapy Requirements

We are submitting public comment on behalf of the Fenway Institute at Fenway Health, a federally qualified health center in Boston, MA that serves 32,000 patients each year. We are writing regarding the proposed rule by the Centers for Medicare and Medicaid Services titled, “Medicare and Medicaid Programs; CY 2020 Home Health Prospective Payment System Rate Update; Home Health Value-Based Purchasing Model; Home Health Quality Reporting Requirements; and Home Infusion Therapy Requirements.”

The proposed rule seeks input regarding the importance, relevance, and appropriateness of several standardized patient assessment data elements (SPADEs)—including sexual orientation and gender identity (SOGI)—under consideration for the 2022 Home Health Quality Reporting Program (HH QRP). We strongly support the proposed inclusion of SOGI data elements as SPADEs in the 2022 HH QRP.

Researchers, providers, and professional health organizations have long agreed that the collection of SOGI data is important and relevant for improving clinical health outcomes for LGBT people and reducing LGBT health disparities. This is why the Institute of Medicine (IOM),¹ the Joint Commission,² and CMS³ all recommend asking questions about SOGI in clinical settings and including these data in EHR systems to improve quality of care. It is also why the Bureau of Primary Health Care at HRSA requires community health centers to report the SOGI of their 20 million adult patients.⁴

The collection of SOGI data is especially relevant in light of the rule’s proposed new category of SPADE data collection regarding the social determinants of health (SDOH). The proposed rule defines SDOH as “socioeconomic, cultural, and environmental circumstances in which

¹ Institute of Medicine. 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. Accessed November 24, 2015.

² The Joint Commission. *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*. Oakbrook Terrace, IL: The Joint Commission, 2010, page 11.

³ Centers for Medicare and Medicaid Services (2015). *Equity Plan for Medicare Beneficiaries*. https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf

⁴ Cahill S (2018). Legal and policy issues for LGBT patients with cancer or at elevated risk of cancer. *Seminars in Oncology Nursing*. 34(1):90-98.

individuals live that impact their health,” and proposes collection of seven new SPADE data elements relating to SDOH including: race, ethnicity, preferred language, interpreter services, health literacy, transportation, and social isolation. It will be important to collect SOGI data alongside these SDOH data elements because LGBT people experience unique cultural and environmental circumstances, especially in terms of anti-LGBT discrimination and stigma, which can negatively impact access to health services and health outcomes.^{5,6} LGBT identity also intersects with the proposed SDOH data elements in unique ways that can create additional barriers to care. For example, social isolation is of special concern for LGBT elders, who are less likely to have children and more likely to live alone compared to their heterosexual peers.⁷ Furthermore, LGBT elders may be afraid to access mainstream elder services due to fear of discrimination, and this can exacerbate social isolation.

LGBT elders are 3-4 times less likely to have children, and more likely to be single and living alone in their old age, compared to heterosexual peers.⁸ LGBT elders are more likely to report being physically disabled or have poor mental health outcomes compared to the general population.⁹ Due to these disparities, LGBT elders may become more reliant upon formal caregiving from home care aides. Older adults who grew up in the 1940s and 1950s, now in their 60s and older, “came of age in a psychosocial environment in which heterosexism, homophobia, and stigmatization were more powerful and less challenged than they are today.”¹⁰ Many LGBT individuals are concerned about experiencing discrimination and neglect from a home care aide, including those coming from countries where strong anti-gay prejudices prevail. LGBT elders may have greater need of elder services, including in-home caregiving assistance, but may be less likely to access these services due to fear of discrimination.¹¹ Collecting SOGI data in the HH QRP is important to understand whether LGBT older adults access home care aides or experience disparities in accessing this important elder service to allow them to age in place.

In addition to being important and relevant for improving health outcomes, SOGI data are also appropriate and feasible to collect. In 2015, the Office of the National Coordinator for Health Information Technology (ONC) adopted SOGI standards as required fields in the “demographics” section of the 2015 Edition Base Electronic Health Record (EHR) Definition certification criteria, making SOGI part of all Certified Electronic Health Record Technology

⁵ 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.

⁶ 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.

⁷ Fredriksen-Goldsen KI, Kim HJ, Emler 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.

⁸ Fredriksen-Goldsen, K. I., Kim, H.-J., Emler, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., . . . Petry, H. (2011). *The aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults*. Seattle: University of Washington.

⁹ Ibid.

¹⁰ Grossman, A. H. (2006). Physical and mental health of older lesbian, gay, and bisexual adults. *Lesbian, gay, bisexual, and transgender aging: Research and clinical perspectives*, 53-69.

¹¹ Stein, G., & Almack, K. (2012). Care near the end of life: The concerns, needs and experiences of LGBT elders. In Ward, R., Rivers, I., Sutherland, M. (eds.), *Lesbian, gay, bisexual and transgender ageing: Biographical approaches for inclusive care and support*. London: Jessica Kingsley Publishers. 114-134.

(CEHRT) products.¹² Further, in addition to being required fields for EHR certification, SOGI have also been included in the *Interoperability Standards Advisory* since it was first published in 2015.¹³ SOGI standards have achieved steadily increasing and high levels of maturity and adoption since 2015, as reflected in the 2019 edition of ONC's *Interoperability Standards Advisory*.¹⁴

Given the importance and relevance of collecting SOGI data for improving health outcomes, especially in connection with the proposed addition of SDOH data elements, as well as the existence of mature and acceptable SOGI data standards, we support the proposed inclusion of SOGI data in the 2022 HH QRP.

Sincerely,

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¹² Office of the National Coordinator for Health Information Technology. (2015). 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Final Rule. Available online at: <https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base>

¹³ Office of the National Coordinator for Health Information Technology. (2015). *2015 Interoperability Standards Advisory*. Page 7. Available online at: https://www.healthit.gov/sites/default/files/2015interoperabilitystandardsadvisory01232015final_for_public_comment.pdf

¹⁴ Office of the National Coordinator for Health Information Technology. (2019). *2019 Interoperability Standards Advisory*. Pages 20-22. Available online at: <https://www.healthit.gov/isa/sites/isa/files/inline-files/2019ISAResponseEdition.pdf>