August 30, 2021

SUBMITTED ELECTRONICALLY

William N. Parham, III
Director, Office of Strategic Operations and Regulatory Affairs
Division of Regulations Development
Centers for Medicare & Medicaid Services
Room C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

Re: Opportunity for Public Comment on Medicare Beneficiary Experiences with Care Survey (MBECS) System Form No. CMS-10701 (OMB Control number: 0938-New)

Dear Mr. Parham:

Whitman-Walker Institute, The Movement Advancement Project, and interACT Advocates for Intersex Youth are LGBTQI+ public health policy practitioners, analysts, and advocates who are pleased to submit these comments regarding the Medicare Beneficiary Experiences with Care Survey (MBECS).

Interest and Expertise

Whitman-Walker Institute conducts research, advocates for just and inclusive policies, and engages in clinical and community education to advance the health and wellness of communities of LGBTQI+ people and people living with HIV (PLWH). The Institute's Research Department currently has more than 2,500 participants in 40+ active studies, and recent research projects include collaborations with several other large LGBTQI-focused FQHCs to identify and address the health needs of marginalized communities. Institute researchers, educators and policy advocates also work closely with the over 200 providers at Whitman-Walker Health, a federally qualified community health center (FQHC) in Washington, DC, to enhance the impact of their health care delivery and to ensure that direct patient care, research, education, and public policy mutually reinforce each other. Whitman-Walker Health has substantial experience and expertise working with Medicare beneficiaries and transgender people: in 2020, over 10% of our patients were enrolled in Medicare, and over 16% of our patients are transgender.

Comments

We strongly support the proposal to update the MBECS to include measures of sexual orientation and gender identity (SOGI) in the core MBECS instrument. Including SOGI measures in MBECS

will help CMS to understand and measure differences in the experiences of sexual and gender diverse Medicare beneficiaries compared with those of the general Medicare population.

The National Academies of Sciences, Engineering, and Medicine recently documented that sexual and gender diverse populations suffer systematic health disparities, economic injustices, and discrimination, with unique and persistent challenges to affirming, competent, and accessible care for older LGBTQI+ adults.[1] As President Biden's equity agenda has noted, a significant driver of these injustices and public health challenges is a lack of consistent data collection on sexual orientation, gender identity, and intersex status, which means that sexual and gender diverse people are invisible to policymakers and providers of health care and other services. Including sexual orientation and gender identity measures on the MBECS is an important aspect of fulfilling the federal government's role in measuring disparities to identify and address inequities.

The lack of consistent, reliable, population-based data on sexual and gender diverse people presents substantial challenges to researchers at community-based health centers, academic institutions, and government agencies. Without population-based data as a benchmark, researchers investigating the health, economic status, and wellbeing of sexual and gender diverse populations cannot know how representative their study samples are of those populations generally. These data are particularly important for CMS, as LGBTQI+ people are more likely to be beneficiaries of CMS programs due to higher rates of poverty, disability, and HIV among LGBTQI+ populations than in the general population.[1]

While nationally representative data on LGBTQI+ adults are lacking, reports estimate that there are between 1.75 and 4 million LGBT people over 60.[2] The CDC reports that, from 2014 to 2018, the largest growing group of PLWH were people aged 65 years or older.[3] Further, LGBTQ+ people are disproportionately impacted by HIV; the CDC estimates that in 2018, 69% of new HIV diagnoses in the U.S. were among gay and bisexual men, and 57% of PLWH are gay and bisexual men.[4] According to the Williams Institute at the UCLA School of Law, 22% of LGBT people in the U.S. are poor, compared to 16% of straight cisgender people.[5] Accurately collecting sexual orientation, gender identity, and intersex status data is an important component of racial equity

[1] National Academies of Sciences, Engineering, and Medicine, Understanding the Wellbeing of LGBTQI+ Populations (Washington, DC: 2020), available at https://www.nap.edu/catalog/25877/understanding-the-well-being-of-lgbtqi-populations.
[2] LGBT Aging: A Review of Research Findings, Needs, and Policy Implications, August 2016, accessed via https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-Aug-2016.pdf .
[3] Diagnoses of HIV Infection in the United States and Dependent Areas, 2018: Persons Living with HIV, accessed via https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/content/living.html#age
[4] The CDC estimates that, in 2018, 69% of new HIV diagnoses in the US were in gay and bisexual men. *See* Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2014–2018. HIV Surveillance Supplemental Report 2020;25(No. 1). http://www.cdc.gov/ hiv/library/reports/hiv-surveillance.html. Published May 2020. Accessed August 30, 2021.
[5] Badgett, M. V. L., Choi, S. K., & Wilson, B. D. M., (2019, October). LGBT poverty in the United States: A study of differences between sexual orientation and gender identity groups. Los Angeles, CA: The Williams Institute.

also, as LGBT people of color, bisexual people, and transgender people are more likely to be poor than other LGBT people.[6]

Many older LGBTQI+ people distrust the health care system because they came of age in an era when the medical establishment pathologized same-sex behavior and gender diversity. Many LGBTQI+ people were subjected to shock therapy or lobotomies, or were committed to psychiatric institutions with the support of mainstream medicine and psychiatry.[7] Understanding the experiences of LGBTQI+ older adults in health care settings is thus critical to ensuring that they are able to access supportive and affirming care throughout their lives. Including questions about sexual orientation, gender identity, and intersex status are critical to understanding beneficiaries' experiences with Medicare and to closing gaps in healthcare quality and access for these populations.

Though we strongly support the inclusion of sexual orientation and gender identity questions on the MBECS, however, we have two specific concerns that we wish to raise. First, the proposed gender identity question, as written, does not accurately identify transgender people. Second, the current proposal for the MBECS questionnaire does not include people with intersex traits.

1. Questions 67 & 68 Fail to Accurately Identify Transgender Beneficiaries

We appreciate Question 66, which follows well-established principles of data collection on sexual orientation. The basic framework of the "two-step" gender identity and sex assigned at birth format of Questions 67 and 68 is also appropriate, though several aspects of the proposed Questions 67 and 68 do not reflect emerging best practices in measurement of gender identity. Specifically, we make the following recommendations for Questions 67 and 68:

Ask about gender identity first.

The CDC's recommendation[8] and the recommendation of leading LGBTQI+ researchers and analysts[9] is that gender identity be asked first, before sex assigned at birth. Asking gender identity first reflects the importance of gender in the lived experiences of all people, both transgender and cisgender.[10]

---

[6] Badgett, M. V. L., Choi, S. K., & Wilson, B. D. M., (2019, October). LGBT poverty in the United States: A study of differences between sexual orientation and gender identity groups. Los Angeles, CA: The Williams Institute.
[7] Blakemore E. Gay Conversion Therapy's Disturbing 19th-Century Origins. HISTORY. Accessed December 17, 2020. https://www.history.com/news/gay-conversion-therapy-origins-19th-century
[8] Collecting Sexual Orientation and Gender Identity Information, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention,Centers for Disease Control and Prevention, https://www.cdc.gov/hiv/clinicians/transforming-health/health-care-providers/collecting-sexual-orientation.html
[9] The GenIUSS Group. (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute, accessed via https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf.
[10] Deutsch MB, Green J, Keatley JA, et al. Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. *J Am Med Inform Assoc.* 2013;20:700–703.

Allow respondents to select all that apply for gender identity, and include a free-text answer option for gender identity.

The option to mark more than one answer choice has not been universally implemented on federal, national-scale U.S. data collections; however, some recent federal and academic data collections, including the National Institutes of Health (NIH) *All of Us* Research Program[11] and the PRIDE Study,[12] have included this feature. Studies and reviews of gender identity questions have found that, for some gender minority individuals, "male" and "female" are not mutually exclusive from "transgender" or "another gender identity."[13,14,15,16,17,18,19,20] A recent study using focus groups and cognitive interviews among sexual and gender minority participants identified the need to allow participants to select more than one answer choice with a "select all that apply" prompt.[13] The ability to select all that apply and inclusion of the answer choice of "Another gender identity (specify)" both clarifies the question is asking about gender identity and provides a write-in option for those who do not find a suitable choice among those provided. These question features are also in line with recently published statistical data collection standards published by the New Zealand government.[21]

---

[11] National Institutes of Health. All of Us Research Program. 2021; https://allofus.nih.gov/, https://www.researchallofus.org/wp-content/themes/research-hub-wordpress-theme/media/spotlight/uploads/AoU_Researcher%20Workbench%20Educational%20Material%20-%20Gender%20Identity_Sex%20Assigned%20at%20Birth_Sexual%20Orientation.pdf, https://www.phenxtoolkit.org/protocols/view/11801?origin=subcollection.

[12] Stanford University School of Medicine. The PRIDE Study. 2021; https://pridestudy.org/.

[13] Suen LW, Lunn MR, Katuzny K, et al. What sexual and gender minority people want researchers to know about sexual orientation and gender identity questions: a qualitative study. *Archives of Sexual Behavior.* 2020;49(7):2301–2318.

[14] Morgan RE, Dragon C, Daus G, et al. Updates on terminology of sexual orientation and gender identity survey measures. FCSM 20-03. Federal Committee on Statistical Methodology. 2020; https://www.bls.gov/osmr/research-papers/2017/pdf/st170210.pdf.

[15] Reisner SL, Conron KJ, Tardiff LA, Jarvi S, Gordon AR, Austin SB. Monitoring the health of transgender and other gender minority populations: validity of natal sex and gender identity survey items in a U.S. national cohort of young adults. *BMC Public Health*. 2014;14:1224.

[16] Tate CC, Ledbetter JN, Youssef CP. A two-question method for assessing gender categories in the social and medical sciences. *Journal of Sex Research*. 2013;50(8):767–776.

[17] Stern MJ, Michaels S, Milesi C, Viox MH, Morrison H. Medicare Current Beneficiary Survey (MCBS) Task 1.32.a: Develop and test sexual and gender minority status (LGBT) items: final summary report. HHSM-500-2014-00035I, Task Order # HHSM-500-T0002. 2016; https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Research-Report-sexual-gender-minority-status-items.pdf.

[18] Ellis R, Virgile M, Holzberg J, et al. Assessing the feasibility of asking about sexual orientation and gender identity in the Current Population Survey: results from cognitive interviews. Office of Survey Methods and Research, U.S. Bureau of Labor Statistics. 2017; https://www.bls.gov/osmr/research-papers/2017/html/st170210.htm.

[19] Holzberg J, Ellis R, Virgile M, et al. Assessing the feasibility of asking about gender identity in the Current Population Survey: results from focus groups with members of the transgender population. Office of Survey Methods and Research, U.S. Bureau of Labor Statistics. 2017; https://www.bls.gov/osmr/research-papers/2017/html/st170200.htm.

[20] Lombardi E, Banik S. The utility of the two-step gender measure within trans and cis populations. *Sexuality Research and Social Policy*. 2016;13:288–296. doi: http://dx.doi.org/10.1007/s13178-016-0220-6

[21] Stats NZ. Statistical standard for gender, sex, and variations of sex characteristics. 2021; https://www.stats.govt.nz/methods/statistical-standard-for-gender-sex-and-variations-of-sex-characteristics.

Specifically, we recommend the following design for the "two-step" question:

Gender:

What is your gender? Please select all that apply.

1. Male

2. Female

3. Transgender

4. Another gender (please specify): _____

Sex assigned at birth:

What sex were you assigned at birth, on your original birth certificate?

1. Male

2. Female

3. Something else (please specify): _____

4. Prefer not to say

The proposed questionnaire does not include people with intersex traits.

Intersex people often have challenging relationships with the health care system. Many have experienced medical trauma related to medically unnecessary genital and sterilizing surgeries conducted in infancy or early childhood without their consent, and unnecessary and objectifying medical examinations.[22] Many experience minority stress related to nondisclosure and concerns related to disclosure of their intersex traits.[23] In a recent study on intersex adults in the U.S., over 43% of participants rated their physical health as fair/poor, and 53% reported fair/poor mental health. Prevalent health diagnoses included depression, anxiety, arthritis, and hypertension, with significant differences by age. Nearly a third reported difficulty with everyday tasks, and over half reported serious difficulties with cognitive tasks.[24] Identifying people with intersex traits to ensure

[22] "I Want to Be Like Nature Made Me." Human Rights Watch. Published July 25, 2017. Accessed December 17, 2020. https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medicallyunnecessary-surgeries-intersex-children-us

[23] Affirming Primary Care for Intersex People 2020. Accessed December 17, 2020. https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/08/Affirming-Primary-Care-forIntersex-People-2020.pdf

[24] Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, et al. A national study on the physical and mental health of intersex adults in the U.S. PLOS ONE. 2020;15(10):e0240088. doi:10.1371/journal.pone.0240088

they are able to access high-quality health care in affirming environments is a compelling interest for CMS across its programs.

Variations in sex characteristics (intersex traits):

> *Were you born with a variation in your physical sex characteristics? This is sometimes called an intersex variation or having a Difference in Sex Development (DSD).*
>
> *1. No*
>
> *2. Yes, my chromosomes, genitals, reproductive organs, or hormone functions were observed to be different from the typical male/female binary at birth and/or I have been diagnosed with an intersex variation or Difference of Sex Development*
>
> *3. Don't know*
>
> *4. Prefer not to say*

Conclusion

Thank you for incorporating sexual orientation and gender identity questions in the proposed update to the MBECS form. We look forward to working with CMS to collect and analyze these data, as well as data on intersex status, to improve the health and wellbeing of LGBTQI+ people and the U.S. population more broadly.

Sincerely,

Kimberly Zieselman, JD
Executive Director
interACT: Advocates for Intersex Youth
kimberly@interactadvocates.org

Naomi Goldberg, MPP
Deputy Director
LGBTQ Program Director
Movement Advancement Project
naomi@lgbtmap.org

Kellan Baker, PhD, MPH, MA
Executive Director
Chief Learning Officer
Whitman-Walker Institute
kbaker@whitman-walker.org