





March 13, 2024

National Committee for Quality Assurance 1100 13th St. NW, Third Floor Washington, D.C. 20005

RE: HEDIS Public Comment (MY 2025), Comment on Cross-Cutting Measures, Gender-Inclusive Measure Adjustment for Chlamydia Screening in Women and Race-Ethnicity Stratification

Dear NCQA Staff and Leadership:

On behalf of the Fenway Institute, National Health Law Program, and Whitman-Walker Institute, undersigned organizations that advocate for LGBTQI+ health equity, we submit the following comments on the proposed changes to HEDIS measures for 2025. We support the proposed 2025 changes to the HEDIS measure "Chlamydia Screening in Women." The changes account for best practice evidence that demonstrates the effect and potential disparities in chlamydia diagnosis and treatment for transgender and gender diverse individuals. However, we oppose the proposed 2025 changes to Race-Ethnicity Stratification in HEDIS measures. The changes would obscure the source of race and ethnicity data and reduce overall data quality. NCQA should continue to require organizations to report the source of race and ethnicity data to ensure that data captured can be appropriately evaluated for quality. NCQA should continue to make changes that encourage quality data capture and input in both the race and ethnicity and sex, gender, and sexual identity demographic spheres.

Support for Gender-Inclusive Measure Adjustment

We support the proposed changes to "Chlamydia Screening for Women," which would require inclusion of all members who fit the criteria for chlamydia screening beyond those identified as women. This change acknowledges the clinical evidence on occurrence of chlamydia in transgender, nonbinary, and gender diverse people and the potential for disparate outcomes for these discrete communities.² Further, this change

¹ Nat'l Committee for Quality Assurance, *HEDIS Public Comment*, https://www.ncqa.org/about-ncqa/contact-us/public-comments/hedis-public-comment-2/ (last visited Mar. 8, 2024).

² In addition to the evidence cited in the proposal, the World Professional Association of Transgender Health (WPATH) cites several other studies examining the inclusion of transgender women in STI testing. See Coleman, E. et al., Standards of Care for the Health of

will enable health programs, providers, researchers, and advocates to better understand health care quality and outcomes for transgender, nonbinary, and gender diverse people by allowing for stratification of measure data by inclusion criteria. We appreciate that NCQA has made gender-inclusive changes to other measures, including breast and cervical cancer screenings, and we believe the 2025 proposed change aligns with NCQA's stated goal of advancing health equity for underserved communities.

Opposition to Race-Ethnicity Stratification Adjustment

We oppose the proposed change to Race-Ethnicity Stratification of HEDIS measures. Eliminating the requirement to report the source of race and ethnicity data will obscure whether data has been self-reported, imputed, or generated from a third-party source. This distinction, which is currently in place, allows programs, plans, providers, researchers, and advocates to assess the quality of demographic data reported—self-reported data being the "gold standard"—and use that information as they interpret race/ethnicity comparisons in health care quality metrics. Removing this requirement disincentivizes programs from improving demographic data quality and jettisons transparency for a critical health equity component of the measure data.

Rather than eliminating this requirement, NCQA should encourage HEDIS users to invest in methods to increase the prevalence of self-reported demographic information. Strategies and resources to improve self-reported data include training for front-line staff; options to solicit demographic self-reporting on program applications, at enrollment, and during encounters; and the ability to crosswalk data between programs.³ Encounter data that is not self-reported, as well as other imputed data, should be used only as a validation measure or back up to self-reported data. Research from the Assistant Secretary for Planning and Evaluation shows that imputed race and ethnicity is more likely to be inaccurate for certain groups including multiracial and

Transgender and Gender Diverse People, Version 8 23 INT'L J. TRANSGENDER HEALTH, S1, S169 (2022), https://www.tandfonline.com/doi/full/10.1080/26895269.2022.2100644.

³ See David Blumenthal and Cara James, *A Data Infrastructure for Clinical Trial Diversity*, New England Journal of Medicine 2 (2022),

https://www.nejm.org/doi/pdf/10.1056/NEJMp2201433?articleTools=true; Ruben D. Vega Perez et al., Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study from a Large Urban Health System, 14 Cureus 1, (2022)

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/; Brittany Brown-Pordgorski et al., *Improving Medicaid Data to Advance Racial and Ethnic Health Equity in the United States*, Health Affairs Forefront (May 24, 2022).

https://www.healthaffairs.org/do/10.1377/forefront.20220517.465853?utm_medium=social&utm_source=twitter&utm_campaign=forefront&utm_content=brown-podgorski.

American Indian/Alaska Native-identified individuals.⁴ In addition, Census research shows that linking data from the Census Bureau with data from other health programs can provide accurate, self-reported information.⁵

This proposed change contravenes the forward movement of health equity measures in that it discourages transparency and the implementation of best practices in data reporting. Therefore, we oppose this proposal.

Conclusion

Thank you for considering our comments on these proposals. For follow up or additional information, please contact Charly Gilfoil, Staff Attorney at the National Health Law Program.

Sincerely,

Fenway Institute
National Health Law Program
Whitman-Walker Institute

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⁴ Melony E. Sorbero et al., RAND Corp., *Imputation of Race and Ethnicity in Health Insurance Marketplace Enrollment Data*, 2015-2022 Open Enrollment Periods (2022), https://aspe.hhs.gov/sites/default/files/documents/931e1e3edec745ea7fdd364f9e28d6c6/asperand-imputation-race-ethnicity-mktplc-rpt.pdf.

⁵ Aubrey Limburg et al., U.S. Census Bureau, *Enhancing Race and Ethnicity Information in Medicaid Data: The Role of Census Bureau Data* (Feb. 2, 2023), https://www.census.gov/library/working-papers/2023/demo/SEHSD-WP2023-05.html.