

March 13, 2023

National Committee on Quality Assurance (NCQA)

Re: Changes to two quality measures for Breast and Cervical Cancer Screening in the Healthcare Effectiveness Data and Information Set (HEDIS)

Submitted to: my.ncqa.org

Dear colleagues,

Fenway Health submits this comment in response to the request for comments on changes to two quality measures for Breast and Cervical Cancer Screening in the Healthcare Effectiveness Data and Information Set (HEDIS).

Fenway Health is a federally qualified health center and Ryan White Part C HIV clinic in Boston, Massachusetts, and one of the world's largest health centers focused on LGBTQIA+ communities. Roughly half of our 35,000 patients are LGBTQIA+, and over 5,000 are transgender and nonbinary. Some 2,200 Fenway Health patients are people living with HIV, and about 3,000 are on PrEP for HIV prevention. The Fenway Institute is the research, training, and health policy division of Fenway Health. Fenway Institute researchers have conducted extensive research on cancer screenings among transgender and gender diverse patients.^{1,2,3,4,5,6,7}

¹ Peitzmeier, S. M., Reisner, S. L., Harigopal, P., & Potter, J. (2014). Female-to-male patients have high prevalence of unsatisfactory paps compared to non-transgender females: implications for cervical cancer screening. *Journal of General Internal Medicine*, 29(5), 778-784.

² Peitzmeier, S. M., Khullar, K., Reisner, S. L., & Potter, J. (2014). Pap test use is lower among female-to-male patients than non-transgender women. *American Journal of Preventive Medicine*, 47(6), 808-812.

³ Potter, J., Peitzmeier, S. M., Bernstein, I., Reisner, S. L., Alizaga, N. M., Agénor, M., et al. (2015). Cervical cancer screening for patients on the female-to-male spectrum: A narrative review and guide for clinicians. *Journal of General Internal Medicine*, 30(12), 1857-1864.

⁴ Reisner, S. L., Deutsch, M. B., Peitzmeier, S. M., White Hughto, J. M., Cavanaugh, T. P., Pardee, D. J., et al. (2018). Test performance and acceptability of self- versus provider-collected swabs for high-risk HPV DNA testing in female-to-male trans masculine patients. *PLoS One*, 13(3).

⁵ Rollston R. *Promoting Cervical Cancer Screening Among Female-to-Male Transmasculine Patients*. Boston: The Fenway Institute (2019). https://fenwayhealth.org/wp-content/uploads/TFIP-28_TransMenCervicalCancerScreeningBrief_web.pdf

⁶ McDowell, M., Pardee, D. J., Peitzmeier, S., Reisner, S. L., Agénor, M., Alizaga, N., Bernstein, I., & Potter, J. (2017). Cervical Cancer Screening Preferences Among Trans-Masculine Individuals: Patient-Collected Human Papillomavirus Vaginal Swabs Versus Provider-Administered Pap Tests. *LGBT health*, 4(4), 252–259. <https://doi.org/10.1089/lgbt.2016.0187>

⁷ McDowell, M., Pardee, D. J., Peitzmeier, S., Reisner, S. L., Agénor, M., Alizaga, N., Bernstein, I., & Potter, J. (2017). Cervical Cancer Screening Preferences Among Trans-Masculine Individuals: Patient-Collected Human Papillomavirus Vaginal Swabs Versus Provider-Administered Pap Tests. *LGBT health*, 4(4), 252–259. <https://doi.org/10.1089/lgbt.2016.0187>

Fenway Health strongly supports NCQA's changes to current breast and cervical cancer screening measures. Screening for cervical cancer should be determined based on presence of an organ and not based on gender or sex. Shifting to an anatomy-based approach to health care is the most accurate way to understand who may need screening, regardless of gender identity or the sex/gender as listed on insurance. Gender identity is important information to capture for all patients, but this alone does not give information about one's anatomy or individual preventive health needs. Adjusting the recommendations for breast cancer screening and cervical cancer screening to include anyone with breast tissue or a cervix will ensure that all relevant individuals are included in outreach, have access and coverage for screening, and are counted in quality measures.

Transgender and nonbinary individuals on the masculine spectrum who retain a cervix likely experience cervical cancer at similar rates to cisgender women. According to the National Transgender Survey, only 8% of respondents who were identified as female at birth had a hysterectomy to remove the uterus and cervix. Of the 92% who retained a cervix, only 27% reported that they had a Pap test in the past year, compared with 43% in the U.S. adult cisgender female population.⁸

Transgender, nonbinary and intersex people may be at increased risk for cervical cancer due to underutilization of cancer screening and delayed follow-up care.^{9,10,11,12} Research indicates that transgender masculine individuals are significantly less likely to have up-to-date Pap tests,¹³ and are more likely to experience unsatisfactory Pap tests, compared to cisgender women.¹⁴ Lower rates of regular screening put trans masculine people at greater risk of late diagnosis, when the disease process may be more difficult to treat.

Breast cancer screening may also be indicated for transgender and gender diverse patients. Chest reconstruction surgery does not remove all breast tissue, but rather leaves residual tissue to create a masculine appearing chest. It is therefore possible to develop breast cancer in this remaining tissue. Based on a patient's family history and other breast cancer risk factors, breast imaging and/or referral to a Breast Clinic may be indicated to ensure that appropriate screening and surveillance occur. It is essential for primary care providers to understand the scope of gender

⁸ James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). Executive Summary of the *Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality. <https://www.transequality.org/sites/default/files/docs/usts/Executive%20Summary%20-%20FINAL%201.6.17.pdf>

⁹ Taylor, E. T., & Bryson, M. K. (2016). *Cancer's margins: trans* and gender nonconforming people's access to knowledge, experiences of cancer health, and decision-making*. *LGBT Health*, 3(1), 79-89.

¹⁰ Peitzmeier, S. M., Khullar, K., Reisner, S. L., & Potter, J., 2014.

¹¹ Connolly, D., Hughes, X., & Berner, A. (2020). Barriers and facilitators to cervical cancer screening among transgender men and non-binary people with a cervix: A systematic narrative review. *Preventive medicine*, 135, 106071.

¹² National LGBTQIA+ Health Education Center, *Affirming primary care for intersex people, 2020*. Boston: The Fenway Institute, 2020. <https://www.lgbtqihealtheducation.org/wp-content/uploads/2020/08/Affirming-Primary-Care-for-Intersex-People-2020.pdf>

¹³ Peitzmeier, S. M., Khullar, K., Reisner, S. L., & Potter, J., 2014.

¹⁴ Peitzmeier, S. M., Reisner, S. L., Harigopal, P., & Potter, J. (2014).

affirming surgeries to offer complete and accurate cancer screening and prevention recommendations. This includes obtaining a full social, anatomical, and family history.

The new proposed denominator criteria for breast cancer screening and cervical cancer screening should increase access for individuals of this anatomy regardless of their gender or sex. This update to the measure will support transgender, gender diverse, and intersex patients in accessing these life-saving preventive cancer screenings. We strongly support this proposed move, which will increase health equity for transgender, gender diverse and intersex patients.

Thank you for this opportunity to provide comment. If you have any questions, please feel free to contact Sean Cahill, Director of Health Policy Research at scahill@fenwayhealth.org.

Sincerely,

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