

March 13, 2023

National Committee for Quality Assurance
Healthcare Effectiveness and Data Information Set (HEDIS)
110013th St. NW, Third Floor
Washington, D.C. 20005
Submitted via My NCQA

RE: Proposed Changes to Gender Documentation and Inclusion in Breast and Cervical Cancer Screening for HEDIS^{®1} MY 2024

To Whom It May Concern,

We are grateful for the opportunity to provide comments to the National Committee for Quality Assurance (“NCQA” or “Department”) regarding its proposed changes to the Healthcare Effectiveness Data and Information set (“HEDIS”) Breast Cancer Screening and Cervical Cancer Screening measures.¹

The undersigned are scholars affiliated with the Williams Institute, an academic research center dedicated to conducting rigorous and independent research on sexual orientation and gender identity (“SOGI”), including on disparities and discrimination experienced by lesbian, gay, bisexual, and transgender (“LGBT”) people. The Williams Institute has long worked with federal agencies to improve data collection on the U.S. population, including producing widely cited best practices for the collection of SOGI information on population-based surveys.²

We write to you in support of the proposed changes to the HEDIS measures to update the definition of all people recommended for routine screening for breast and cervical cancer. This update acknowledges that individuals in need of these cancer screenings may have a diverse set of gender identities and experiences, while previous guidelines were limited by their focus on “females.” There is currently very little data or research done on the rate of breast and cervical cancer among transgender and gender nonbinary people (hereinafter “transgender people”). Important areas with little or missing information include access to cancer screenings, participation in preventative screenings, and the quality of medical treatment received.³

¹ National Committee for Quality Assurance. (March 13, 2023). *HEDIS Public Comment: Proposed Changes to Gender Documentation and Inclusion in Breast and Cervical Cancer Screening for HEDIS^{®1}*.

<https://www.ncqa.org/wp-content/uploads/2023/02/03.-Gender-in-Measurement.pdf>

² 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.). The Williams Institute.

<https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf>; Sexual Minority Assessment Research Team (SMART). (2009). *Best Practices for Asking Questions about Sexual Orientation on Surveys*. The William Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf>.

³ Oladeru, O. T., Ma, S. J., Miccio, J. A., Wang, K., Attwood, K., Singh, A. K., Haas-Kogan, D. A., & Neira, P. M. (2022). Breast and Cervical Cancer Screening Disparities in Transgender People. *American journal of clinical oncology*, 45(3), 116–121. <https://doi.org/10.1097/COC.0000000000000893>

Existing research indicates that transgender people experience discrimination and disparities related to health care access. For example, research done by the Williams Institute shows transgender individuals consistently report significantly lower rates of preventative care compared to their cisgender adult counterparts. In California, 39% of transgender adults had no preventative care visit during the past year compared to 28% of cisgender adults,⁴ and nationally, 20% of transgender adults report that they have no place to go for their healthcare.⁵ According to a report from the 2015 U.S. National Transgender Survey, “Only 27% [of transgender adults assigned female at birth] reported that they had a Pap [test] in the past year, compared to 43% in the U.S. adult population.”⁶ A lack of provider and patient knowledge about the necessity of routine screening may further disparities in health outcomes.⁷

Provider bias and discrimination when seeking care are also major factors impacting breast and cervical cancer screening among the transgender population. For example, a national survey showed 62% of transgender people worry about being negatively judged when seeking healthcare.⁸ New guidelines could help to increase provider awareness and patient access to inclusive care, leading to an increase in early detection and quality treatment options.

Similar changes to the ones proposed by NCQA have been suggested in the context of HPV screening to increase awareness of early risk factors and detection among sexually active transgender individuals with a cervix.⁹ These changes would help to bring quality measures in line with the most recent version of the World Professional Association for Transgender Health’s (“WPATH”) Standards of Care.¹⁰ Less invasive, patient-centered HPV testing via self-swabbing has been studied as a potential solution to increasing the rate of early screening, especially for

⁴ Babey S.H., Wolstein J., Herman, J.L., & Wilson, B.D.M. (2022). *Gaps in Health Care Access and Health Insurance Among LGBT Populations in California*. UCLA Center for Health Policy Research. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/CA-Health-Care-Gaps-Feb-2022.pdf>

⁵ Feldman J.L., Luhr W.E., Herman J.L., Poteat T., & Meyer I.H. (2021). Health and health care access in the US transgender population health (TransPop) survey. *Andrology*. <https://doi.org/10.1111/andr.13052>

⁶ James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). *The Report of the 2015 U.S. Transgender Survey*. National Center for Transgender Equality. <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>

⁷ Weyers, S., Garland, S. M., Cruickshank, M., Kyrgiou, M., & Arbyn, M. (2021). Cervical cancer prevention in transgender men: a review. *BJOG : an international journal of obstetrics and gynaecology*, 128(5), 822–826. <https://doi.org/10.1111/1471-0528.16503>

⁸ Meyer, I.H., Wilson, B.D.M., & O’Neill, K. (2021). *LGBTQ People in the US: Select Findings from the Generations and TransPop Studies*. The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf>

⁹ Mohr, S., Gygax, L. N., Imboden, S., Mueller, M. D., & Kuhn, A. (2021). Screening for HPV and dysplasia in transgender patients: Do we need it?. *European journal of obstetrics, gynecology, and reproductive biology*, 260, 177–182. <https://doi.org/10.1016/j.ejogrb.2021.03.030>

¹⁰ Coleman, E., Radix, A. E., Bouman, W. P., Brown, G. R., de Vries, A. L. C., Deutsch, M. B., Ettner, R., Fraser, L., Goodman, M., Green, J., Hancock, A. B., Johnson, T. W., Karasic, D. H., Knudson, G. A., Leibowitz, S. F., Meyer-Bahlburg, H. F. L., Monstrey, S. J., Motmans, J., Nahata, L., Nieder, T. O., ... Arcelus, J. (2022). Standards of Care for the Health of Transgender and Gender Diverse People, Version 8: Section 15.10. *International journal of transgender health*, 23(Suppl 1), S151–S152. <https://doi.org/10.1080/26895269.2022.2100644>

those who may experience physical or emotional discomfort during gynecological exams.¹¹ Any changes to these measures should look to such research to help improve quality of patient-provider interactions and uptake of screenings. Medical providers may have difficulty determining the appropriateness of various breast cancer imaging and treatment options for transgender patients, therefore education on updated guidelines is needed to help increase provider knowledge.¹²

We recommend that NCQA also include guidance for ethical use of these insurance records and incorporate controls around misuse of these data into the existing accountability mechanisms used by the organization, such as through accreditation considerations. Although the disclosure of personal medical information is strictly regulated under federal law such as the Health Insurance Portability and Accountability Act (“HIPAA”)¹³ and some state and local laws may offer additional protections against discriminatory use of information, even entities and individuals with potentially lawful access to records may choose to use them to harm transgender patients. For example, elected officials in Florida¹⁴ and Missouri¹⁵ have recently requested, and in the case of Florida, received information about young people obtaining gender-affirming care through state-funded providers. In Arkansas, state law explicitly permits insurance providers to deny gender-affirming care.¹⁶ Therefore, NCQA should ensure to the greatest extent possible that these changes do not contribute to denial of care for transgender patients, particularly in states without SOGI or nondiscrimination protections.¹⁷ One approach to this consideration might be an evaluation of the impact of the changes after implementation.

Lastly, we recommend that NCQA assess the impact of these changes for intersex people. Intersex people are born with (or develop naturally in puberty) genitals, reproductive organs,

¹¹ See footnote 7; Reisner, S. L., Deutsch, M. B., Peitzmeier, S. M., White Hughto, J. M., Cavanaugh, T., Pardee, D. J., McLean, S., Marrow, E. J., Mimiaga, M. J., Panther, L., Gelman, M., Green, J., & Potter, J. (2017). Comparing self- and provider-collected swabbing for HPV DNA testing in female-to-male transgender adult patients: a mixed-methods biobehavioral study protocol. *BMC infectious diseases*, 17(1), 444. <https://doi.org/10.1186/s12879-017-2539-x>

¹² Clarke, C. N., Cortina, C. S., Fayanju, O. M., Dosssett, L. A., Johnston, F. M., & Wong, S. L. (2022). Breast Cancer Risk and Screening in Transgender Persons: A Call for Inclusive Care. *Annals of surgical oncology*, 29(4), 2176–2180. <https://doi.org/10.1245/s10434-021-10217-5>; Expert Panel on Breast Imaging, Brown, A., Lourenco, A. P., Niell, B. L., Cronin, B., Dibble, E. H., DiNome, M. L., Goel, M. S., Hansen, J., Heller, S. L., Jochelson, M. S., Karrington, B., Klein, K. A., Mehta, T. S., Newell, M. S., Schechter, L., Stuckey, A. R., Swain, M. E., Tseng, J., Tuscano, D. S., ... Moy, L. (2021). ACR Appropriateness Criteria® Transgender Breast Cancer Screening. *Journal of the American College of Radiology : JACR*, 18(11S), S502–S515. <https://doi.org/10.1016/j.jacr.2021.09.005>

¹³ Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996).

¹⁴ Mabe, A. (February 22, 2023). Ron DeSantis requested the information of trans students who sought care at Florida's public universities. Now students are planning a statewide walkout. *The Insider*. <https://www.insider.com/ron-desantis-trans-college-students-medical-records-florida-medical-care-2023-2>

¹⁵ Migdon, B. (February 10, 2023). Hawley launches investigation into Missouri children's hospital, demands records of 'gender-related treatments' for youth. *The Hill*. <https://thehill.com/homenews/state-watch/3852798-hawley-launches-investigation-into-missouri-childrens-hospital-demands-records-of-gender-related-treatments-for-youth/>

¹⁶ ARK. CODE ANN. § 23-79-166(c) (West 2021)

¹⁷ See e.g. *Equality Maps: Public Accommodations Nondiscrimination Laws*, MOVEMENT ADVANCEMENT PROJ. (MAR. 1, 2023), https://www.lgbtmap.org/equality-maps/non_discrimination_laws/public-accommodations.

and/or chromosomes that do not fit standard definitions of male or female.¹⁸ While insufficient research has been done to date to identify the range of health needs of intersex populations, research suggests that intersex people experience poorer health than is typically observed in the general population.¹⁹ The changes proposed by NCQA could potentially allow better health outcomes and better measurement for some intersex patients. However, further research could support making additional recommendations to accommodate those with variations in sex characteristics, including the possibility of accommodating anatomical inventories in future releases, as discussed in the proposed revisions.

We commend the NCQA for the proposed revisions to gender inclusion measures in an effort to ensure that “all members who are recommended for routine breast and cervical cancer screenings receive the screening.” The resulting data would help us to better understand the health disparities among gender minority populations and advance inclusive care. Thank you for your consideration.

Respectfully Submitted,

Erica Browning, M.P.H.
Research Data Analyst
The Williams Institute
UCLA School of Law

Jody L. Herman, Ph.D.
Senior Scholar of Public Policy
The Williams Institute
UCLA School of Law

Christy Mallory, J.D.
Legal Director
The Williams Institute
UCLA School of Law

Elana Redfield, J.D.
Federal Policy Director
The Williams Institute
UCLA School of Law

¹⁸ (GENIUSS) GROUP, *supra* NOTE 2, citing Hida Vioria, *OII-USA Submission to the National Institutes of Health Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender and Intersex Populations*.

¹⁹ See e.g. Amy Rosenwohl-Mack et al., *A National Study on the Physical and Mental Health of Intersex Adults in the U.S.*, 15 PLOS ONE 10 (2020).

Brad Sears, J.D.
Founding Executive Director
The Williams Institute
UCLA School of Law

Andrew R. Flores, Ph.D.
Visiting Scholar
The Williams Institute
UCLA School of Law

Ilan Meyer, Ph.D.
Distinguished Senior Scholar of Public Policy
The Williams Institute
UCLA School of Law

Kerith Conron
Distinguished Senior Scholar and Research Director
The Williams Institute
UCLA School of Law

William Tentindo
Law Fellow
The Williams Institute
UCLA School of Law