Gender in Breast & Cervical Cancer Screening

March 13, 2023

To the National Committee for Quality Assurance:

The undersigned LGBTQI and allied organizations represent national, regional and local communities invested in cancer, sexual and gender minority health, and racial/ethnic health disparities.

Transgender and gender-diverse populations face a variety of cancer care inequities and barriers to care, resulting in delayed cancer diagnoses, inadequate treatment, and worse clinical outcomes.[1] We agree that it is critical to ensure that quality measurement advances cancer screening and quality of cancer care for these populations without inadvertently excluding already under-represented populations.

We appreciate that the National Committee for Quality Assurance (NCQA) has offered the opportunity to comment on their ongoing work to address gaps in cancer screening and quality measurement for transgender, gender-diverse, and intersex populations.

We strongly support NCQA's overall momentum towards gender inclusivity through the revision of quality measure descriptions and specifications. Revision of the denominators for the Breast Cancer Screening (BCS) and Cervical Cancer Screening (CCS) measures is an important step towards inclusion of transgender and gender-diverse populations in quality measurement. As NCQA works to update their cancer screening measures and other quality measures, it is important to note that organ-based inclusion criteria, rather than gender-based criteria, will best promote inclusion and appropriate care for all beneficiaries, regardless of gender identity or medical history.

With that in mind, we detail below several considerations and recommendations for these HEDIS updates, particularly regarding the consideration of intersex individuals.

1. **Expand the proposed inclusion criteria for BCS to include all individuals ages 50-74 with 5 or more years of exposure to gender-affirming estrogen therapy, regardless of their administrative gender, sex assigned at birth, or sex for clinical use.** The NCQA proposed revisions better align with clinical screening guidance for trans and gender-diverse adults.[2] However, to streamline specifications and anticipate the potential for inadvertent exclusion from this denominator, we recommend expanding this proposed inclusion criteria to include all individuals ages 50-74 with 5 or more years of exposure to gender-affirming estrogen therapy, regardless of their administrative gender, sex assigned at birth, or sex for clinical use. This expansion would help ensure that nonbinary people, people with x as their sex on their birth certificate, and/or intersex people are not inappropriately excluded.

[1] Jackson SS, Han X, Mao Z, et al. Cancer Stage, Treatment, and Survival Among Transgender Patients in the United States. J Natl Cancer Inst. 2021;113(9):1221-1227. doi:10.1093/jnci/djab028

[2] Fenway Health (2021). Medical Care of Trans and Gender Diverse Adults. https://fenwayhealth.org/wp-content/uploads/Medical-Care-of-Trans-and-Gender-Diverse-Adults-Spring-2021-1.pdf

2. **Evaluate BCS inclusion and exclusion criteria as they relate to intersex populations.** The health needs of intersex populations—those born with innate variations in physical sex characteristics—are insufficiently understood, but there is evidence that these populations face health disparities and barriers to care, including in sexual and reproductive health.[3] For these populations, current categories such as sex assigned at birth and sex for clinical use will often be unable to reflect relevant patient anatomy, risk factors, and screening needs.[4] This may result in both over- and under-screening for patients with particular intersex variations. NCQA should (a) evaluate the feasibility of a general, overall measure of variations in sex characteristics to inform more nuanced screening decisions,[5] and (b) evaluate particular intersex variations to determine whether they should be added as inclusion criteria or exclusion criteria beyond previous mastectomy.[6]

3. **Move these revisions forward quickly.** It is urgent to ensure inclusivity in the BCS measure. CMS has signaled that they may update the BCS measures used in their value-based care programs based on how NCQA proceeds with updating their inclusion criteria.[7] Importantly, the BCS measure is intended to be included in CMS' planned Universal Foundation measure set, signifying that the updated measure may be applied universally across all CMS value-based programs. It is therefore critical to ensure inclusivity for this foundational measure.

Ensuring inclusivity in the CCS measure is also a priority. We support the inclusion of transgender and gender-diverse members with a cervix in the intent and description of this measure, since there are substantial disparities in cervical cancer screening for transgender individuals.[8] However, additional work is necessary to ensure that intersex individuals are considered in the inclusion and exclusion criteria for this measure.

It is likely not appropriate for intersex individuals to receive cervical cancer screenings if they do not have a cervix. For instance, the American College of Obstetricians and Gynecologists does not recommend routine cytology testing for individuals with Müllerian agenesis because of the lack of a cervix, but these individuals would currently fall into the CCS measure's denominator.[9] Broadly including the "Specified" option under "sex for clinical use" may inappropriately call for screening intersex members who do not

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[3] National Academies of Sciences, Engineering, and Medicine. 2020. Understanding the Well-Being of LGBTQI+ Populations. Washington, DC: The National Academies Press. https://doi.org/10.17226/25877.

[4] Center for LGBTQIA Health Education, Affirming Primary Care for Intersex People (2020), https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/08/Affirming-Primary-Care-for-Intersex-People-2020.pdf/.

[5] *See* National Academies of Sciences, Engineering, and Medicine. 2022. Measuring Sex, Gender Identity, and Sexual Orientation, 139-50. Washington, DC: The National Academies Press. https://doi.org/10.17226/26424.

[6] *See* interACT: Advocates for Intersex Youth, Intersex Variations Glossary (2022), https://interactadvocates.org/wp-content/uploads/2022/10/Intersex-Variations-Glossary.pdf.

[7] CMS. February 1, 2023. Advance Notice of Methodological Changes for Calendar Year (CY) 2024 for Medicare Advantage (MA) Capitation Rates and Part C and Part D Payment Policies https://www.cms.gov/files/document/2024-advance-notice.pdf#page=106

[8] 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

[9] The American College of Obstetricians and Gynecologists. Müllerian Agenesis: Diagnosis, Management, and Treatment. https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2018/01/mullerian-agenesis-diagnosis-management-and-treatment

have a cervix or for whom cervical cancer screening is otherwise not recommended**. NCQA should evaluate individual conditions that are classified as intersex or differences in sex development to determine whether they should be added as inclusion criteria or exclusion criteria** beyond "total hysterectomy or acquired absence of cervix". [10] [11] We reiterate that organ-based inclusion criteria, rather than gender-based criteria, will best promote inclusion and appropriate care for all beneficiaries, regardless of gender identity or medical history.

We further encourage future changes to other measures with gender-based inclusion criteria. NCQA's quality measures for PSA screening, osteoporosis management, chlamydia screening, and prenatal and postpartum care should all be considered for changes, as they currently may inadvertently exclude transgender and gender diverse members due to gender-based inclusion criteria. Potential measures for consideration include:

- The measure for **Non-Recommended PSA-based Screening in Older Men (PSA)** currently assesses "whether **men** 70 years of age and older were screened unnecessarily for prostate cancer using prostate-specific antigen (PSA)-based screening." [12]
- The measure **Osteoporosis Management in Women Who Had a Fracture (OMW)** currently "assesses **women** 67-85 years of age who suffered a fracture and who had either a bone mineral density test or a prescription for a drug to treat osteoporosis in the six months after the fracture." [13]
- The **Chlamydia Screening in Women (CHL)** measure currently measures "The percentage of **women** 16–24 years of age who were identified as sexually active and who had at least one test for chlamydia during the measurement year." [14]
- The **Prenatal and Postpartum Care (PPC)** measure assesses access to prenatal and postpartum care through timeliness of prenatal care, "The percentage of deliveries in which **women** had a prenatal care visit in the first trimester, on or before the enrolment start date or within 42 days of enrolment in the organization," and postpartum care, "The percentage of deliveries in which **women** had a postpartum visit on or between 7 and 84 days after delivery."[15]

Gender-based language in the above measures should be revised to include transgender and gender-diverse individuals appropriately and avoid inappropriate exclusions of these populations. The work that NCQA has already done to advance cancer screening quality measurement for these populations will be foundational to this work.

We support the overall concept of stratification to better identify disparities in care. To this end, **we support the proposed race and ethnicity stratification of the CCS measure** and other measures

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[10] The Fenway Institute/InterACT. (2020). Intersex Data Collection: Your Guide to Question Design. Available: https://interactadvocates.org/intersex-data-collection/.

[11] National Academies of Sciences, Engineering, and Medicine. 2022. Measuring Sex, Gender Identity, and Sexual Orientation. Washington, DC: The National Academies Press. https://doi.org/10.17226/26424.

[12] National Committee for Quality Assurance (NCQA) (2023). HEDIS. Non-Recommended PSA-Based Screening in Older Men (PSA). https://www.ncqa.org/hedis/measures/non-recommended-psa-based-screening-in-older-men/

[13] NCQA (2023). HEDIS. Osteoporosis Management In Women Who Had a Fracture (OMW). https://www.ncqa.org/hedis/measures/osteoporosis-management-in-women-who-had-a-fracture/

[14] NCQA (2023). HEDIS. Chlamydia Screening in Women (CHL). https://www.ncqa.org/hedis/measures/chlamydia-screening-in-women/

[15] NCQA (2023). HEDIS. Prenatal and Postpartum Care (PPC). https://www.ncqa.org/hedis/measures/prenatal-and-postpartum-care-ppc/

included in NCQA's HEDIS updates**.** We also support prioritization of the PSA measure for future race/ethnicity stratification. Researchers have noted that differences and disparities in screening practices across race and ethnicity are likely to play a role in treatment and health outcome disparities.[16]

We strongly encourage NCQA to build on this important effort to identify disparities across social factors by **collecting and stratifying measure performance across sexual orientation, gender identity, and sexual characteristics (SOGISC) categories**. Stratification by SOGISC categories would support the identification of disparities in care for sexual and gender minority groups, a well-established issue.[17] The collection, stratification, and reporting of SOGISCI data is especially relevant for cancer screening measures (both BCS and CCS) and other measures covering significant disparities and gaps in care among gender and/or sexual minority groups.[18]

We appreciate that NCQA has offered the opportunity to comment on their important work to promote high-quality and equitable care, including the advancement of cancer screening quality measurement for transgender and gender-diverse groups. Please feel free to contact us at scout@cancer-network.org or 401-26QUEER should you have any questions on our comments.

Organizational signers:

A Fresh Chapter (a project of Social & Environmental Entrepreneurs)
CA LGBTQ Health and Human Services Network
Callen-Lorde Community Health Center
Cancer Support Community
Carrie's TOUCH
CenterLink: The Community of LGBT Centers
Equality California
For the Breast of Us
FORGE, Inc.
GLMA: Health Professionals Advancing LGBTQ+ Equality
Howard Brown Health
HRC
interACT
Liver Coalition of San Diego
Living Beyond Breast Cancer
Lyon-Martin Community Health Services
Movement Advancement Project
National Center for Lesbian Rights
National Center for Transgender Equality
National Coalition for LGBTQ Health
National Health Law Program
National LGBT Cancer Network
Planned Parenthood Federation of America
Project Life
SAGE (Advocacy and Services for LGBTQ+ Elders)
Sharsheret
The Breasties
The Center for LGBTQ Health Equity, Chase Brexton Health Care
Transhealth
Trillium Health
Triple Negative Breast Cancer Foundation
Whitman-Walker Institute
Young Survival Coalition

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[16] Rebbeck T. R. (2018). Prostate Cancer Disparities by Race and Ethnicity: From Nucleotide to Neighborhood. Cold Spring Harbor perspectives in medicine, 8(9), a030387. https://doi.org/10.1101/cshperspect.a030387
[17] Arnold E, Dhingra N. Health Care Inequities of Sexual and Gender Minority Patients. *Dermatologic Clinics*. 2020;38(2):185-190. doi:10.1016/j.det.2019.10.002
[18] Domogauer J, Cantor T, Gwendolyn Q, Stasenko M. Disparities in cancer screenings for sexual and gender minorities. *Current Problems in Cancer*. 2022;46(5): 100858. 10.1016/j.currproblcancer.2022.100858.